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The Difference That Made a Difference: Nuances of a Transformative Curriculum in the Life History of Joy Hamilton, a Child Who Has Severe Disabilities.

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THE DIFFERENCE THAT MADE A DIFFERENCE: NUANCES OF A TRANSFORMATIVE CURRICULUM IN THE LIFE HISTORY OF JOY HAMILTON, A CHILD WHO HAS SEVERE DISABILITIES

A Dissertation

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in

The Department of Curriculum and Instruction

by
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B.A., Louisiana Tech University, 1972
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To Joy, teacher and agent of my transformation.
As different as we are in circumstance,
our hearts beat as one.

As the old man walked the beach at dawn, he noticed a young man ahead of him picking up starfish and flinging them into the sea.

Finally catching up with the youth, he asked him why he was doing this. The answer was that the stranded starfish would die if left until the morning sun.

"But the beach goes on for miles and there are millions of starfish," countered the other. "How can your effort make any difference?"

The young man looked at the starfish in his hand and then threw it to safety in the waves. "It makes a difference to this one," he said.

Anonymous

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painstakingly provided constant and lengthy correspondence with me that added greatly to my understanding. I am indebted to her for her unyielding expectations for clarity and excellence and for guiding my progression to a holistic view of reality.

The scale of the contribution of "Diane" and "Robert Hamilton" is too great to be merely acknowledged. They provided the initial impetus to start this project and courageously permitted, even encouraged me to study the life of their daughter. Fearlessly opening their own lives to me, they trusted me with some of their innermost, private thoughts in the hope that others might learn and understand, and one day, perhaps, live happier and fuller lives.

Special thanks are due to the former special education staff at "JTS Special School." Working together we not only shared a vision of what is possible and desirable, but we lived it. These individuals continue to be a treasured source of support. Their strong belief in the school which is now only a memory, offered inspiration and nourishment at the right time. Their stories of their present dilemmas often pulled me out of a slump and renewed my motivation, giving me the "push" to move forward; throughout this work I could feel their encouragement pressing me forward.

I am thankful to "Maria Lopez" who, in generously opening her classroom to me, shared her beginning

experiences of teaching with me and allowed me to become a part of Joy's classroom experiences.

I am also thankful to the "significant others" who were consulted during the course of the research, but who, for reasons of confidentiality, will not be listed by name.

I extend special appreciation to my family; to my husband for being so giving and supportive and for reviving my sense of humor on countless occasions. I was lucky to have him pushing and prodding until this project was completed; to my daughter Carmen, and my sons, Craig, and Trey, go my thanks for waiting. Finally I wish to express my gratitude--more than gratitude--for my parents' love, support, and encouragement. Though, during the course of my studies, they went on to a better world, they abide with me. Their pride in my work and always believing in me no matter what the circumstances are an indelible memory.

To all these individuals, for all their help, thank you.

FOREWORD

A life history approach is used in this study to examine how curriculum has affected the life of a child who has severe disabilities. What unfolds in Joy's life history is a concern not whether her special education programs worked, but how they worked. It is less about what we can do for children who have disabilities than it is about people and what we must do for each other. To that end, it reveals the distorted lens through which we have viewed our efforts to educate children who have severe disabilities and thus helps us see ourselves as we are. It has been a privilege to accompany Joy and her parents for major portions of Joy's life journey. For Joy's journey has also been mine, and much of what is presented here is what we learned together.

This study chronicles Joy's educational experiences beginning with her infant intervention program and continuing through her preschool years to her current early elementary program. A description of her parents' courtship and early marriage is presented as a backdrop to the story of Joy's life. It captures the innocence of a young couple disempowered and poorly prepared for the enormity of the responsibility suddenly thrust upon them with the birth of a child who has severe disabilities. It is a personal story of Joy's parents as they followed medical counsel that recommended out-of-home placement for their child and then

ultimately, their conflict with the medical model of the residential facility that does not reflect their private goals and aspirations, but is one on which they must depend for support.

As the story of her preschool years unfolds, we see a special education program guided by alternative holistic principles struggle to survive and ultimately collapse within the dominant medical model of the institution where it is housed. With the closure of the program, Joy is transferred to a community special school that is also deeply entrenched with mechanistic practices and procedures. As the limiting effects of the medical model of the institution where she lives and the practices of the special school she attends descend on Joy, she turns inward. Consequently, we see her parents emerge to confront a special school program that assumes the cause of Joy's passive, inward state lies within Joy and her limitations.

What is unusual about Joy's story is that her parents stopped trusting the school because they recognized the contradiction between the Joy they knew and the school's depiction of her based on her impairments. What is commonplace about her story is the institutional culture that made these events possible.

Joy's life history is a paradox. On the one hand, it is a cautionary story of educational decision making gone wrong--a story of reliance on a mechanistic model that

allows the participants to forget that there is a real child involved; a story of a mechanistic model that focuses on what Joy is unable to do rather than on what she is capable of doing; a story of a mechanistic model that potentially dismissed not only the existence of Joy's abilities but also, in a certain sense, the existence of Joy herself.

On the other hand, Joy's story is one of hope--a story of an alternative holistic model that starts from the characteristics of being human; a story of a holistic model that empowers all its participants; a story of a holistic model that focuses on what Joy is capable of doing rather than on what she is unable to; a story of a holistic model that takes inner goal-directedness and inner mean-making to be the primary characteristics of human life and learning; a story of a holistic model with a process of learning that is transformative, includes choices, and provides the way for new possibilities for learning to spring forth.

Those who are responsible for the growth and development of children who have severe disabilities need to understand the limiting effects of the dominant mechanistic model from the child's and the family's point of view. Equally important is to also understand from the child's and the family's point of view the liberating and qualitative changes that radiate from an alternative holistic approach. This study provides such a view.

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ABSTRACT

Literature emerging in the field of special education advocates a significant departure from the traditional approach that has guided special education practices, procedures, and, ultimately the decisions made about children. To date, this literature and the debates it generates are focused primarily on special education for children who have mild or moderate disabilities. The dearth of information regarding the implications of an alternative approach for children who have severe disabilities is wanting.

This study examines the life history of Joy Hamilton, a child who has severe disabilities, to reveal how curriculum has affected her life. Joy's birth, her infant intervention and preschool programs, early elementary educational experiences, and her parents' hopes and concerns for her future are described in detail. As the story of her educational experiences unfold, it reveals how principles of an alternative transformative curriculum are manifested in the education of a child who has severe disabilities. Themes are analyzed relative to the findings of other researchers advocating an alternative approach to education.

The primary methods employed in this research are the unstructured interview and participant observation. A secondary method is the collection of information from outside sources and archival records.

This study provides a detailed holistic view of the life of a child whose life experiences and world view are inaccessible by traditional interviewing and observation techniques. It is significant for the light it sheds on an alternative approach to special education and represents a unique and valuable contribution to the growing body of qualitative research being used in the field. This research is important since the numbers of infants who are born with severe disabilities and survive are significantly increasing in this country. It points to a need to reconceptualize theory, practice, and research to enhance normalization of their lives, allowing them to participate as much as possible in normal life experiences of the general population. Although this study is the life history of one child, the discoveries are not only about her education. What unfolds in her life history generates questions and frames issues relevant to an alternative approach to education for all children.

CHAPTER I

INTRODUCTION

> *Joy is bored...I know she is! She's just not doing all the things she used to do. [Her father] and I aren't happy. We know her program isn't what it used to be. We go into her classroom, and we get bored, too. We look in the other classrooms when we pass in the hall, and it's the same thing...nothing really exciting is happening. I think it's the whole school. Things were so different when she was at Johnston Special School. There was a difference, a big difference in how things were done there and where she is now. I don't know exactly how to say it, but...well, I guess you can say it's something we felt when we walked in the door [of Johnston]...a feeling...you know what I mean? I wish it could be like it was before. If her teachers could only see what she was doing before. I wish you would go over there...go to the school and see for yourself. Look at Joy. You'll know what we mean. Look at her school, her program, and you'll see why she's bored. This is her second year over there, and she gets worse every time we go see her.*
>
> *--Diane Hamilton*

This voice is that of the mother of a child who has severe disabilities. It expresses the way she deeply understands her child's current situation and the special school program she attends.

Another voice with a similar version sums up the feelings of Robert Hamilton, the father of the child:

> It doesn't seem like any of the children like Joy are learning much. It looks like the teacher does most of the work, and she can't get to all six or seven of them [the children] at one time. The parapro-fessionals don't seem to do much...Maybe they don't know what to do. It just looks like baby-sitting to me.

At the same time, consider the clear direction of a section of the official philosophy of the special school Joy attends:

> Evansville Special School...provide[s] a learning environment adapted to the special needs of Baylor District students, enabling them to develop their maximum potential in the areas of cognitive, motor and psycho-social skills (Evansville Special School Teachers' Manual, Revised October 1986, p. 3).

Promoting a commitment of change in order to allow each child the chance to be what he or she is able to become is a statement that forms a fitting background for the in-depth examination of the life of Joy Hamilton. Juxtaposing her parents' personal perceptions of Joy's current situation with the school's formal philosophy punctuates the inadequacies inherent in special education theory, practices, and research. Although most educators consider appropriate special education in terms of federally mandated student evaluation, placement, and curriculum, quality special education for children who have severe disabilities is fundamentally an issue of values and attitudes tied to the process of social change.

This study of the life history of Joy Hamilton, a child who has severe disabilities was undertaken to closely examine how curriculum has affected her life. It is a story that remains focused on Joy, but it is also about her parents, teachers, school administrators, support staff, medical staff, and her extended family as they all live the daily challenges and struggles of participating in social

change. Though their names are pseudonyms, their activities, reactions, and dilemmas are neither fabricated nor manipulated. This chapter provides an introduction to this study. The next section discusses the scope of the study and briefly defines a transformative curriculum. The second part of the chapter describes the appearances and expressions of the child whose life history this study illuminates. A discussion of the duration of the study follows in part three and includes the questions that direct the flow of the study. The fourth section clarifies the phrase *children who have severe disabilities* and discusses my relationship with Joy. It is followed by a section that examines the legal and political background of special education for this population of children. The final section reflects back on the previous sections with a rationale for the study.

Scope of the Study

Joy was 7-years-old at the onset of this study and lived at Johnston Training School (JTS), a privately operated residential facility. She has lived at JTS since she was two years old and, over the five-year span, has attended two special school programs. JTS Special School (also designated as Johnston Special School) was a program sponsored by the Baylor District School Board that was housed on the campus of the institution. JTS Special School provided preschool special education and related

services to Joy from September 1984 to August 1986, when the Special School was dismantled. I was directly involved with Joy's educational experiences at JTS, having served as principal of the special school until its closure. Joy continued to receive special education services at Johnston for the next two years in a classroom that remained at the facility. In August 1988 all rudiments of the special school program were removed from the campus of the institution, and Joy was bused to a community special school, Evansville Special School. A comparison of how curriculum at these two schools (Johnston and Evansville) affected Joy's life offered an ideal site to unearth the potential that an alternative approach holds for children who have severe disabilities. Discriminating aspects of her special education programs at both schools were analyzed within the framework of my theoretical concerns regarding education for children who have severe disabilities. Stated briefly, my concerns are that behaviorist ideology deeply embedded in teaching strategies for this population stifles the living energy of the teacher-student relationship, inhibits developing inclinations of the child to self-direct, and is concerned more with conditioning the child to make a desired response than her or his inner mean-making. Drawing on the arguments of scholars calling for an alternative approach to education (presented in Chapter II), this study aims to

examine how a view of learning that is socially constructed both individually and communally manifests itself in the education of a child who has severe disabilities.

A Transformative Curriculum

I situated a "transformative curriculum" as conceptualized by Doll (1988, in press) within the alternative holistic conception of special education espoused by Heshusius (1982, 1986, 1989) and others (see Chapter II) to provide a vehicle for comparing Joy's special education programs. A holistic conception of special education, which reverses the traditional mechanistic approach to education, requires a redefinition of curriculum. Rather than a linear measured preset order that precedes instruction, curriculum becomes "the process we engage in when we teach and learn with our students" (Doll, 1988, p.130).

The implication of a transformative curriculum grounded in a holistic approach for children who have severe disabilities is not limited to teachers and classrooms. The conceptual framework extends across many environments (hospital, home, school, community, and others) and includes all persons responsible for the growth and care of the child (parents, hospital team, habilitation staff, infant educator, teachers, therapists, paraprofessionals, and others). For a child born with severe disabilities, it begins with the development of an

early intervention program for the infant and her or his family (as mandated by P.L. 99-457 in 1986). I will return to a more in-depth discussion of a transformative curriculum in Chapter II to prepare the way for a review in Chapter VII of its implications in Joy's life.

Joy's Appearance and Expressions

Joy is seven years old and, like her father, has a lean, tall body build. Her straight, thick dark brown hair has lots of body and golden highlights that radiate in sunlight. Neatly trimmed bangs frame her oval face and conceal slightly misshapened contours of her forehead. Her dark hair and gracefully arched eyebrows complement her smooth, olive complexion. People often comment about Joy's strikingly large blue eyes and thick, long eyelashes, which are other features that resemble her father's.

Paralysis of her upper and lower extremities restricts Joy's movement. Although her arms and legs appear to be equally affected, she has more voluntary use of the left side of her body. Joy reaches out to touch objects, particularly those that make noise, with her left hand and has more purposeful movement of her left leg than her right. She is unable to walk independently, but bears weight on her feet when assisted by adults in a standing position or supported in a stander. Joy can sit unsupported for short periods of time but requires support to maintain proper body alignment when sitting for longer

periods of time. She holds her head erect for several minutes when actively engaged in activities.

Noise, movement, touch, and other stimuli elicit response from Joy. Understanding of some daily routines is demonstrated as Joy assists in dressing herself by holding out her arms and legs. She also holds her hands under flowing water to rinse them. She says "ēa" for eat, "mū" for music, " oŭ-si" for outside, "ice," "Coke," "Ma-ma," "Da-duh," "bee-bee" for baby, "uh-oh," "bye-bye," and other one- and two-syllable words.

Smiles and random vocalizations are an indication that Joy is experiencing pleasure. When she is really excited, she thrusts her head and upper trunk backward and extends and elevates her legs and feet forward, with her left leg and foot slightly more elevated than her right. She laughs out loud spontaneously in response to funny incidents.

Joy shows recognition of significant others in her life. When her mother, father, and younger brother visit her, an immediate change in Joy's behavior is observed. She often begins to babble, or "talk," incessantly in louder tones and expresses excitement with whole body movements and banging her legs and feet. She has also been observed to begin "singing" when her parents enter the room.

Although Joy's hearing appears to be functionally appropriate for conversational levels, her vision is

significantly impaired. She responds to light and appears to see shadows and movements. As with most children who have severe visual impairment, Joy relies very much on her hearing and touch to learn about her surroundings. When spoken to, Joy will immediately quieten, remain very still, lower her head and turn it toward the direction of the voice she hears, and fix her eyes in the opposite direction as if trying very hard to hear and concentrate on what is being said.

Joy is a friendly child who has many preferences. Her favorite foods are her mother's mashed potatoes with cheese and pancakes with syrup. She also likes mashed fruits, coke floats, Kool-Aid, and having someone to assist her as she drinks from a water fountain. Her favorite activity is listening to music. She has her own cassette tape player and collection of children's songs, which her parents have consistently added to over the years. She has many favorite songs and "sings" along when she hears them. She anticipates stanzas and choruses of songs and waits for some cue, perhaps tempo, lyrics or rhythm, to "chime in" at the appropriate time. For example, when listening to an audio tape of her little brother singing the "Batman" song, Joy anticipates the chorus and, at the appropriate time and in sequence with her brother's voice, vocalizes "da-nuh, da-nuh, da-nuh, da-nuh...Batman!" Other activities that Joy likes are going outdoors, water play, and going to

children's movies and live productions such as *Sesame Street, Live!* She especially enjoys the musical entertainment in movies and live productions and frequently "sings" along.

Another activity that Joy enjoys is what her mother refers to as "Daddy play." She likes to be talked to and touched, and one can sense the pleasure she derives from the back and stomach rubs her father gives to her. As he strokes her back and sings to her, Joy smiles and vocalizes with him. The rigidity of her arms and legs seems to melt, and her body appears to relax momentarily. She enjoys her father's soft touch as well as his more "aggressive" physical play. She likes to be swept up from a reclining position, moved briskly, rolled, and swung back and forth. Motion is stimulating to Joy, and when her father abruptly changes her position or tickles her sides, she bursts forth with laughter. Their father-daughter relationship is very special.

Just as she has preferences, there are things that Joy does not like. She refuses to drink milk or juice and eat pureed ham or steamed rice. In fact, she prefers food with a smooth texture and does not like any foods with grainy textures. She strongly dislikes drinking from a cup, so a straw or squirt bottle is used when she eats to ensure that she gets proper liquid intake. Most of all, Joy detests abrupt, significant changes in her environment. She

appears to be strong-willed and demonstrates a firm resistance to unfamiliar surroundings with people she does not know.

Joy's mother carefully selects age-appropriate, fashionable clothing for Joy, complete with the latest accessories for her hair. She has several dresses for church and special occasions, but, like most girls her age, Joy most often wears pants and tops. Because she is lean, slacks with elastic at the waist and oversized tops with sleeves are her most common attire. Not only does this style of apparel fit her better, but it also helps to retain her body heat. This is a concern because, unlike most children her age who move about briskly, restricted movement of Joy's arms and legs and low muscle mass inhibit naturally occurring body movements required to maintain her body heat. She wears cotton knit slacks and loose-fitting tops year round, even in summer, since shorts and sleeveless tops do not provide the warmth her body requires. Her outfits are brightly colored and complement her skin tone. In addition to complimentary remarks about the beauty of Joy's eyes, people often comment about the healthy glow of her skin. Her skin tone is such that every color she wears becomes her, from deep hues of burgundy or emerald green, to brighter shades of fuchsia or jade, to lighter pastels. She has several outfits with logos and neon colors, which are presently popular with elementary

school girls. High-top sneakers, color-coordinated socks, and fashionable barrettes round out her wardrobe.

To summarize, Joy is a friendly child who is strong-willed. She anticipates and actively participates in her surroundings, but severe physical impairments inhibit the extent to which she is able to communicate this to others. She enjoys being with and interacting with familiar persons. Laughter and "singing" typically characterize her social traits. Despite having been institutionalized since she was two years old, Joy remains strongly bonded to her parents who advocate effectively for her and continue to be actively involved in her life. Although the institution where Joy lives is in a neighboring state about a two-hour drive from their home, the Hamiltons have maintained regular contact with their daughter. They visit her often and frequently contact habilitative personnel and her special education teacher to inquire about Joy's status. In the five years that Joy has lived at Johnston, both of her parents have attended all facility and educational planning conferences scheduled for her. Also remarkable is the fact that Joy has spent most holidays and special occasions at home with her family. The only exception was Mother's Day 1990, when her parents, who were recovering from illnesses that required hospitalization, were not able to bring Joy home. This life history describes in detail Joy's present

circumstances, how she came to be in those circumstances, and her parents' hopes and concerns for her future.

Duration of the Study

Beginnings of the Study

I became acquainted with Joy and her parents in the fall of 1984 when Joy, who was 2-years-old, was admitted to Johnston Training School. As mentioned earlier, I was principal of JTS Special School. My direct involvement in her special education program ended, however, in the fall of 1986 when the special school was dismantled. Three years lapsed with no contact with Joy or her family. Therefore, a telephone call from her parents one evening in August 1989 came as a surprise and rekindled my interest in Joy and family. The concerns they expressed, which opened this chapter, gave impetus to this study and my desire to probe deeply beyond statistical data of IEPs and evaluation reports to understand Joy's present situation and to uncover the meanings of the differences in her programs.

My personal involvement in Joy's preschool program, however, presented a dilemma. On the one hand, I felt compelled to follow the advice of Bogden and Biklen (1982) who urge novice researchers to study sites where they are not directly involved; on the other hand, I was lured by the fact that successful studies have been accomplished by people who were personally involved in the places they studied [e.g., McPherson, 1972; Rothstein, 1975 cited in

Bogden and Biklen (1982); Becker, 1963; Roth, 1963; Riemer, 1977 cited in Taylor and Bogdan (1984)]. Moreover, I was encouraged by Langness and Frank (1988) who caution researchers that "it is usually not advisable to attempt a life history until one has known the person and/or been in the field for some reasonable period of time" (p. 39).

A drawback to conducting this study was related to Joy's placement at JTS. She was approaching her eighth birthday at which time, according to JTS guidelines, she would be transferred to another facility (outside the immediate area). Field based study at Evansville would therefore be limited to one semester.

Progression of the Study

The project spanned more than two years (four years considering the two years that I was directly involved with Joy's preschool program) and included three phases. The first phase began in the fall of 1989 and consisted of gathering archival records including medical reports, school records, family records and photograph albums, and similar documents. Mid-term 1990 marked the second phase of the research and included one semester of field based study at Evansville Special School. This phase necessarily ended when Joy was transferred to an institution in a neighboring state. The third phase of the study partly overlapped with the second phase and continued throughout the writing of this study. During this phase archival

records, field notes, and transcripts of taped interviews were analyzed. Interviews were continuously conducted and Joy's parents, other family members, school personnel, and significant others were asked to verify information and my perceptions.

My Interest

The special school at JTS was dismantled in 1986, reportedly due to declining enrollment and local and state budget cuts. The former staff's memories of the children, their work with them, and their relationships with the parents, which created the life of the school, lingers on in their hearts and minds. Consider some of their comments:

> School secretary: It was so special...the staff ...their great attitudes...the children. It is a loss, a real loss to the children [that the program was withdrawn], and the "higher ups" don't even seem to care.
>
> Paraprofessional: I learned so much and felt like we accomplished so much. Paraprofessionals in PTUs in other schools aren't given the opportunities we had...They're treated like lower-class citizens...like they don't count.
>
> Special Education Teacher: In the six years [that I taught in Baylor District] before coming to JTS Special School, I never felt that I was treated like I am a professional [teacher]. Not until I worked there...and, I haven't felt that way since.
>
> Therapist: There's nothing like JTS Special School that can compare. I didn't realize it then, but what we were doing was so far beyond what is going on in other programs around here. We were way ahead of the times six years ago and far ahead of what is going on now.

> Special Education Teacher: It was good...good for the children...good for us...good for the parents. It was good, very good!

The program was a very special one, and I am fortunate to have been a part of it. Over the years the voices of former staff members have raised my consciousness about the uniqueness of the program and have stirred a longing to understand the differences that set the program apart from others. Certainly, we had a qualified, caring staff that tried to do the best it could for the children, but so have other programs.

Through the years that I have worked in Baylor District, I have visited the special school Joy currently attends on several occasions. Outwardly, the school appears to be more like Joy's preschool program than different: It is located in the same geographical location; it is regulated by the same LEA; it has "approved" special school status from the State Department of Education; the teachers are certified special educators; the therapists are licensed; similar materials and equipment are used; the special education coordinator assigned to monitor the IEPs and assist in the evaluation of the teachers served both schools; the people providing services appear to be caring individuals who are dedicated to the children.

Where does the difference lie? What was life like for Joy in her preschool program? What is life like for her

now? What is the difference that made a difference in her life and, I might add, in the lives of her parents and teachers?

These questions convey the focus of my study. I want to learn about the life of Joy. I want to recapture the life of her preschool program and learn about the life of her current school, in depth, in detail, and in the interactions and involvement of the people there. Rather than enumerative data, it is the discovery of meanings from those involved in her life that will allow me to understand her current situation and grasp the meaning of the "elusive" difference in her programs.

"Children Who Have Severe Disabilities"

Terminology in the field of special education is often confusing and changing. For example, although "disability" generally refers to an individual's condition and "handicapped" refers to the consequence in society, these terms were used interchangeably in EAHCA (1975), the major federal law mandating education for all children who have disabilities (Gartner & Lipsky, 1987).

Congress amended EACHA on October 30, 1990, changing the name of the law to the Individuals with Disabilities Education Act (IDEA) to recognize that people, including children are the true focus of the legislation. In addition, all references to "handicapped children" were changed to "children with disabilities." To illustrate how

the meaning of disability is differentiated from the term *handicapped*, I share a personal example of a dialogue with my six-year-old son, but first I must add a note about his perceptions of children who have disabilities. Because of the nature of my work, Trey is more familiar with children who have severe disabilities than those who have mild or moderate disabilities. This dialogue will reveal that in Trey's world, children who have severe, multiple disabilities--those who are unable to communicate verbally, have little motor control, are non-ambulatory, and have vision and hearing impairments--typically represent children who have disabilities. Becoming acquainted with a child who has a physical disability but is able to communicate verbally and move his arms independently is a novel experience for Trey. I have picked my son up from a summer day program at church, and he is excited about a new friend he just met. As we drive home, Trey describes his friend to me:

> Trey: Jarred can't walk. But, he can move his arms and he can talk...English, like you and me! (Trey is accustomed to the use of gestures and guttural utterances as the means by which children who have severe disabilities "talk.") And, he can play with cars and trucks! He has a kinda wheelchair...you know, it's not big. It's little...down on the ground...not a high one. It's got big wheels at the back and little ones in the front.
>
> Mom: Oh, I know what you mean. It looks like a go-cart but doesn't have a motor.
>
> Trey: Yeah, he uses his arms to make it go. I said his wheelchair is his "Ferrari." He can move fast as I can! When we go outside, we take big boards and

lean 'em up to the steps. We have two of 'em...one to go in and one to go out. (Apparently, a temporary ramp is used at the entrance to the building and another to the rear of the building where the children exit to go to the playground.) He can go on the slide!

Mom: How does he do that? Does someone take him out of his "Ferrari" and hold onto him as he goes down the slide?

Trey: No, he goes in his "Ferrari"...you know, over [the slide], under, and all around (motioning with his hands).

Mom: Oh, it's not the kind of slide with steps that you climb. It's a ground slide, the kind with an arch that you can go over and under?

Trey: Uh-huh!

Mom: I see what you mean.

Trey: He gets stuck in the chips, though, and we have to pull him out. His wheels go down, and he can't move!

To differentiate between "disability" and "handicapped," we say that Jarred has a disability. He is apparently unable to walk due to paralysis of his legs and moves about in a mobility cart. Jarred is handicapped, however, due to the consequences of environmental barriers; the building is inaccessible without the use of temporary ramps, and the surface of the playground (wood chips) impedes the mobility of his travel cart and thus restricts his being able to move about freely in outdoor play. Although he is handicapped by his physical surroundings, it appears that Jarred is presently not handicapped by disabling attitudes of his peers. It occurred to me that as Trey and I talked, he did not use "handicapped" to

describe Jarred. He simply stated, "Jarred can't walk." The children seemingly accept Jarred as he is and enjoy playing with him, setting up the ramps for him to use, and "pulling him out of the chips." Examples like this are an indication that our society is changing.

Returning to the issue of terminology, "severely disabled" or "severely handicapped" are terms that are used both diagnostically and generically. Special educators and school psychologists use the classification "severely handicapped" to indicate the extent of a student's intellectual functioning and the particular education program and related services she or he is entitled to under IDEA. The American Association on Mental Deficiency defines "severely handicapped" as the following:

> a generic term used to refer to individuals who have serious handicaps that are predicted to continue for long term or life; it includes a high proportion of persons at the moderately, severely, and profoundly retarded levels. (Grossman, 1983, p. 195)

In this study I avoid stereotypic and therefore pejorative terminology such as "severely disabled," "severely handicapped," "quadriplegic," etc. I prefer to use the phrase *children who have severe disabilities* to indicate that they are children first, who happen to have severe disabilities. Like all children, they are complex individuals who have additional characteristics as well. I do not use the phrase to judge their abilities, but to locate them in our schools. These children have many

untapped abilities. This differentiation, *children who have severe disabilities,* is used only for clarification. Because this study chronicles the life of a child from her birth to eight years of age, I use the term *children* rather than students. Somehow "student" did not fit her infant and preschool years. The term is not to imply that all individuals, including adolescents and adults with severe disabilities are regarded as "children." I use this phrase inclusive of all children who have severe, multiple, or profound disabilities--even those who have the most severe disabilities. Borrowing from Sailor, Gee, Goetz, and Graham's (1988) "working definition" of this population, these children have a wide range of multiple impairments in combination with severe intellectual impairment, which causes a profound loss of functioning. Most have various orthopedic and sensory disabilities and little or no voluntary control over their movements. Many are medically at risk, chronically ill, or medically dependent, while some may have extremely severe behavior disorders. They may or may not demonstrate obvious choices or preferences, signs of anticipation, or affect. This description, I might add, includes children diagnosed as "brain stem functioning" or "comatose." Holding to the premise that all children can learn, it seems appropriate, I believe, that a chance should be taken with those few possibly permanently unresponsive youngsters.

I say "possibly" permanently unresponsive because I have observed that even these children are capable of responding. Consider the example of Adrian, a child who who also lived at JTS. Adrian suffered massive brain damage as a result of physical abuse when he was two months old. Shortly thereafter, he was declared a ward of the state and institutionalized. His placement occurred four years prior to EAHCA, and for years Adrian lay on his back in a hospital crib most of the time. His body was rigid and fully extended with firmly fixed joints. He lay motionless, as if frozen in time. Glancing at Adrian when passing by his crib, one often did a double take since he looked so lifeless. Any voluntary movement of his head or extremities was absent. Although there was limited range in his shoulder and hip joints, contractures of his knees and elbows prevented his legs and arms from bending. His back could mold slightly the curvature of an infant seat or floor-sitter when he was placed upright in a supported sitting position, but because his knee and elbow joints were frozen, his legs stiffly extended horizontally and his arms dropped vertically. Reflexive, involuntary movement was almost nonexistent. His large eyes glared and rarely did his eyelids blink. Thus, medication was routinely administered to keep his eyes lubricated.

Adrian was fed with a gastrostomy tube inserted into his abdomen. His mouth was open and dry most of the time,

and his lips were cracked from his breathing through his mouth. He had a "bird chest," so called because of the enlargement of his chest cavity and oversized lungs, which developed from his labored breathing.

In spite of the severity of his disabilities, there were three important aspects of Adrian's condition that may be considered relative "strengths." Most important was the fact that Adrian was breathing without a mechanical aid. Although his breathing was labored, it was regular; therefore, he was not on a respirator. In addition, Adrian responded overtly to pain. Though he did not twitch or cry, tears welled in his eyes and rolled down his cheeks when injections were administered to him by the nurse. A third relative strength was that Adrian was remarkably healthy despite his physical frailty. He was seldom ill, and the nurse often commented that he was the healthiest child in the ward.

The medical staff permitted only bedside special education services for Adrian. He appeared to be unconscious not only of his surroundings, but also of his own body. He did not seem to have awareness of his mouth, which may have been due in part to his being tube fed. His insightful teacher, experimenting with ways to assist Adrian in becoming aware of his body, received permission from the nursing staff to place a peppermint stick in Adrian's mouth to see if he would respond. Telling him he

was about to get his first taste of candy, the teacher held one end of the stick of candy, placed the other end on Adrian's tongue, then gently rolled the peppermint stick around the inside and top of his mouth. Adrian moved his tongue slowly, then gently opened his mouth wider as if to signal "more." He made no sound as the teacher softly stimulated his mouth. His only response was slight movement of his tongue and jaw, but as the teacher walked away, she heard a barely audible gurgle. Perceiving the sounds to be a call for her to return, she went back to his crib. As she talked to him and lightly stroked his face, the sounds subsided. Response, even the most subtle, keeps hope alive--realistic hope for another small progressive step.

My Relationship with Joy

To explain my relationship with Joy required a look inward. How is it that my life connects with Joy's? How did my passion for quality education for all children--particularly those who have severe disabilities--evolve? Where am I coming from? How did I get here? Where am I going?

The answers to these questions lie in my own life history which has given permanence and identity to the individual that I am. Sharing my personal reflections is not an easy task. But, as I begin to write these down, I realize that my story is worth telling, because sharing

experiences helps everyone to learn. In retrospect, it seems that my parents' relationship with the child of a relative has perhaps had the greatest influence on my values and beliefs about children who have severe disabilities. Paul is one of triplets born to my father's cousin and her husband 45 years ago. Paul's infant sister died within hours after their births and, as their father puts it, "It was 'nip and tuck' with Paul and Pete. We didn't know if they were going to make it." The first few days were critical, for the boys suffered anoxia at birth. Pete, who as a child always liked to let it be known that he was three minutes older than Paul, is ambulatory with knee braces and walks with an unsteady gait. He has good communication skills and his mother's sense of humor. Pete received twelve years of regular education and attended a semester or two of college. Paul, however, is unable to walk and therefore confined to a wheelchair for mobility. He has limited control of his muscles and is unable to flex his fingers, but has learned a compensated grasp and release. Maintaining his head in midline is an effort for Paul, and by the end of the day his head is often slumped forward. Although his speech is slow and labored, it is intelligible.

We lived next door to Paul's family when I was a young child, and I have many cherished memories of my parents' enduring relationship with him. Looking back, I can see my

mother assisting Paul's mother to place him on the school bus that took him to a special school. I see myself walking home from school to eat lunch so I can wait with Mother to greet Paul when he arrives home. The wheelchair lift on the bus is both fascinating and frightening to me. I see Dad hurry next door to apply an apparatus to their telephone, which he hopes will enable Paul to use the rotary dial. I see Dad helping Paul's father build a ramp at their backdoor for Paul's wheelchair. I see them convert an ordinary backyard into a specialized exercise course for the boys. This is my first time to see a posthole spade, and I watch with rapt attention as my father digs holes into the ground, then fills them with concrete to stabilize bars that are placed at just the right height for Paul to practice lifting himself out of his wheelchair. These were happy times. But, I also recall a period of extreme anguish: Shockwaves pulsated throughout both families when we received the news that Paul could no longer attend his special school. He was six years old when school personnel informed his parents that Paul failed to score at least 50 points on an IQ test and therefore was considered "ineducable." Without at least a 50 IQ, so his parents were told, there was "no hope"; Paul could not learn. Insensitive and tactless describes the manner in which they were told the news. Paul's father recalls, "The man wasn't diplomatic about it at all. In

Pete's presence he said that Paul was not capable. His IQ was too low. It really bothered Pete."

Betrayal summed up my mother's feelings regarding the school's rejection of Paul. Paul and Pete were charter members of the independently operated school, which was organized primarily by a physician who had a son with disabilities and a small group of supporters. School administrators released photographs of Paul and Pete (stunning pictures of adorable twin boys) to the media to publicize drives and fund raisers for the school. Disillusioned with the school, Mother felt that school administrators used Paul and Pete to solicit funds for the school, then abandoned Paul.

My father's reaction to this turning in Paul's life was more overt than that of my mother. Paul's dismissal from school was to him an atrocity. His words seemed unusually potent and remain fixed in the depths of my being:

> Those doctors and teachers think they know it all! They look at Paul and because he can't move like them or talk like them or write his name, they say he's retarded, he can't learn. But, he's got a good mind. They don't know him. They just don't know him. He can learn. They're supposed to be the experts, but they don't know nearly as much as they think they do.

Following Paul's dismissal from school, Pete transferred to our neighborhood elementary school, and Paul was sent home. I grew up knowing how talented and inspiring a person is Paul. As a young child it was

confusing to me that teachers did not believe that he could learn. Paul and I were near the same age, yet I knew that he had talents and interests that far exceeded mine. For example, as a young boy, Paul was an accomplished short-wave radio operator. Many isolated, lonely hours at home were spent occupying himself with his radio. Turning the knobs to fine-tune the sound was a laborious task, but Paul managed to do it with skill. He even kept a log of his contacts, an activity my father taught him. His radio was Paul's friend, but his first love was politics. Paul appreciated a good debate. He was on top of all the elections and knew who was running for what office. He enjoyed rooting for his favorite candidate and arguing against the opponents.

At the end of my second year in school, our family moved to my parents' hometown. We rarely saw Paul and his family except at annual family reunions. At these gatherings it struck me that, unlike many relatives who would speak to Paul and perhaps give him a pat on the shoulder as they walked past, Dad would pull up a chair next to him, and they would talk and talk and talk. Through the years Paul has suffered periods of deep depressions lasting from a few days to weeks at a time. When things were not going right with Paul, it seemed to affect my father as well. Upon hearing that he was having a "bad spell," Dad often called Paul long distance to cheer

him up; but, as it so frequently happened, it was Paul who lifted my father's spirits.

Paul and my father had a very special relationship. Dad was Paul's devoted, faithful supporter, and, Paul adored my father. When Dad walked into the room where Paul was sitting, it was like magic. The two of them lit up the room. As Paul's father puts it, "They had a special rapport." When they were not arguing politics, Dad was playing the guitar (at a slower than usual tempo) as he and Paul crooned their favorite Hank Williams songs. Paul was fascinated with keys, particularly automobile keys, and could identify each one in a collection he kept. When Dad visited Paul, he somehow managed to have an extra key in his pocket to leave with him. Shortly after my father's death, my sister and I were cleaning his office and recovered the old battered box of discarded keys that he had been saving over the years to give to Paul.

Before leaving a discussion of my parents' relationship with Paul, I should mention a significant aspect of his past that is relevant to this study. The school that dismissed Paul was Evansville Special School, the school Joy was attending when this life study was conducted.

Now, returning to a discussion of Joy. As I embarked on this study, my relationship with Joy picked up where it left off more than three years ago. I was very much in the

role of professional educator. But as the study progressed and I probed deeper into her past, our relationship grew. I have acquired an abiding interest in Joy and a concern for her well-being. Having penetrated her life experiences at the depth this study required, my knowledge and understanding of her educational experiences has brought to light a fresh and enlarged view of my professional role and responsibilities to children like Joy and their parents. As we spent more time together, my relationship with her parents grew more relaxed. Diane and Robert confided in me. In the course of my living the life of a life history researcher, I have been in touch with the struggles and suffering of Joy and her parents. And, I have learned that once you enter the life struggle of another person, you can never go back. We have built, I believe, a life-long trust.

I entered Joy's world as a person who came to learn. The transforming effect that Joy has had on my life is much more profound than I could have ever imagined. I have been touched by her in ways that I could not foresee. Joy has entered my life also and helped me to see things differently. I have been changed.

Legal and Political Background

Landmark legislation enacted in 1975 provided a legal basis for parents' demands for appropriate education for their children who have disabilities. Public Law 94-142

(1975), the Education for all Handicapped Children Act (EAHCA) guaranteed children who have disabilities a free, appropriate education designed to meet their individual needs. Built into the law was a zero reject provision that required appropriate education for all children, regardless of the type and severity of their disabilities. In addition, the law mandated that first priority students were to be those who were not served and for whom services were inadequate--a provision that clearly pertained to students who have severe disabilities. Thus, the schoolhouse doors across America were opened for a population that had previously been denied access--children who have severe disabilities.

The significant growth in the numbers of children who have severe disabilities cannot be ignored. Improvements in newborn care and technology have increased the survival of "high risk" infants, many of whom have severe disabilities at birth or acquire them later. Corresponding to the increased prevalence of birth defects due to genetic and environmental interaction, such as alcohol and drug addiction, AIDS, and the increase in teen pregnancy, is a broad and growing spectrum of recently mandated early intervention programs. Public Law 99-457 (1986), an amendment to EAHCA, extends the educational rights of all children who have disabilities to include infants and toddlers, ages birth to two years of age.

An irony to the commitment to early intervention is the unsettling challenge to special education for children who have severe disabilities. As the push for full-service mandate of the new federal early intervention program is felt across the nation, the provision of special education for children who have severe multiple disabilities continues to generate controversy. Despite the zero exclusion provision built into EAHCA of 1975, protection afforded children who have severe disabilities continues to be challenged in the courts. A New Hampshire federal judge in *Timothy W. v. Rochester* (1988) ruled that the public school was not obligated to provide special education for a child who has severe disabilities noting that "[his] activities were passive (with little, if any, purposeful movement)" and stating that "the potential for learning seemed non-existent." Although this decision was overturned on appeal and educational rights for children who have severe disabilities were resounded when the United States Supreme Court petitioned by the school district to review the case denied the petition, it is likely that the educational rights of these children will continue to be challenged. Advocates, educators, and policy makers should not view such challenges with acquiescence, assuming that the rights of these children will continue to be protected by law. That it is worthwhile to learn to reach and grasp, be attentive to one's surroundings, initiate interaction,

integrate sensory input, recognize significant others, swallow and chew, sit, stand, walk, or communicate basic needs and desires cannot and should not be argued in terms of benefit, or "educability," or the level of achievement that may be attained. Educational rights for children who have severe disabilities is fundamentally a moral issue. Champagne (1990) in a commentary of *Timothy W.* reminds us that "Congress, after all, did not pass the Education for Almost All Handicapped Children Act. Congress said 'all' " (p. 590).

In spite of the recent affirmation of educational rights for children who have severe disabilities by the Supreme Court, it is conceivable that dominant theory, practice, and research in special education aimed at quantifying student progress may significantly reduce services to these children and eventually deprive many of them of their hard-won right to an education. Measuring student progress in terms of the months of progress achieved according to developmental tests (for example, 1 to 2 months of progress in communication over a year) rather than the qualitative changes in the child over time, often does not, as we shall see in Joy's case, represent actual growth and development. The importance of moving beyond traditional special education approaches to improve the quality of our efforts to provide services to children who have severe disabilities cannot be overstated.

Rationale for the Study

Over the past seventeen years, services for children who have severe disabilities have moved from a state of being virtually ignored to a broad and growing spectrum of services, commanding significant attention from teachers, researchers, advocates, and policy makers. The burgeoning interest in providing public school services to these individuals, many of whom were in private schools or in institutions prior to 1975 (Scheerenberger, 1983), led to an explosion in curriculum development, teacher training, teacher certification, and the marketing of specialized equipment and technology for this population.

Educational services for children who have severe disabilities have indeed increased and changed since being mandated by law. One fundamental aspect of their education, however, remains relatively the same: Instructional practices for this population continue to be deeply embedded in traditional behaviorism and reinforcement theory that postulates forces initiating changes in human behavior to be external to the individual. Mechanistic instructional practices aimed at conditioning the child to make a desired response appears to be the universally accepted approach to teach this population (Snell, 1983). Accordingly, Individual Education Programs (IEPs) are no more than "a course to be run" (to use

Doll's, 1988 remark) with behavioral objectives that follow a sequentially ordered curriculum of isolated skills.

Research advocating an alternative approach to special education (see Chapter II) overflows with references to children with mild and moderate disabilities, their programs, and the potential benefits to these children. There is a recognizable silence in the field, however, regarding children who have severe disabilities. These children, their programs, and the potential advantage an alternative approach holds for them remain relatively obscure in current debates. To contribute to the field of special education by filling in the research gaps, this study became an investigation of the educational experiences of Joy within the context of her life history from the perspectives of all those involved in the life of her programs. The original questions guiding the study (see pp. 15-16) were expanded to include the following: Are the present techniques that dominate the field of special education for children who have severe disabilities the only or primary way to teach these children? Rather than current approaches which are aimed at having the child react in a machine-like manner with an expected response, is there an alternative approach to the education of children who have severe disabilities that starts from the characteristics of being human? How may tenets of an alternative holistic approach that takes inner goal-

directedness and inner mean-making to be the primary characteristics of human life and learning be translated into education for a child who has severe disabilities? How does an alternative transformative curriculum manifest itself in the education of a child who has severe disabilities?

In addition to the light this study may shed on the quality of our efforts to provide special education for children who have severe disabilities is a corresponding significance in relation to the full inclusion of these children into society and the normalization of their lives. Regular education teachers, school administrators, and members of the general public are increasingly in contact with children who have severe disabilities in our schools and in our communities. Perhaps accounts like this that point to a need to reconceptualize theory, practice, and research that guide decision making in the field of special education can contribute to the full inclusion of these children and normalization of their lives.

This study contributes to the growing body of life history research being conducted with persons who have disabilities. Unlike most life history research that is directed at an analysis of themes and patterns among adults who have mild and moderate disabilities, this study attempts an analysis of themes and issues in the world of a child who has severe disabilities. It is an effort to

permit readers to assume the perspectives of the parents, significant others, and to some extent the "perspective" of the child whose life story it tells. This investigation provides an opportunity to see the child's world, including the service delivery system with an emphasis on early intervention and special education, from the "insiders" point of view. Such a perspective is extremely valuable for educators, policy makers, medical professionals and others who are attempting to provide the best services in a time of growing need, controversy regarding the "educability" of children who have severe disabilities, and diminishing resources. Education for this population, however, cannot and should not be argued in terms of level of attainment or achievement. It has a moral dimension; one which views children who have severe disabilities as individuals with implicit rights.

Plan of Dissertation

Following this introductory chapter, Chapter II traces the evolution of special education for children who have severe disabilities and discusses recent debates that call for a re-examination and reorganization of the field. Chapter III fully describes the life history approach and the design of this study. Chapter IV introduces the life history of Joy with the story of her parent's courtship and early marriage as a backdrop to Joy's birth and infancy. It includes the story of her infant intervention program

and the events that led to her institutionalization. Chapter V is the story of her preschool educational experiences at Johnston. Chapter VI provides an accounting of her early elementary experiences at Evansville Special School. Chapter VII examines the themes of a transformative curriculum that emerged in Joy's life history. The final chapter, Chapter VIII, is a reflective review of the discoveries of the study analyzed within the broader context of the purpose of schooling in America.

CHAPTER II

REVIEW OF RELATED LITERATURE

The conception of education as a social process and function has no definite meaning until we define the kind of society we have in mind.

--John Dewey (1916/1968, p. 97)

An important criterion for judging the quality of a society, as President Kennedy reminded us, is how its dependent and less fortunate people are treated (President's Panel on Mental Retardation, 1962). Only recently has our educational system attempted to distinguish itself by this criterion. For the most part children who are different because of race, gender, culture, language or disability have not had full and fair access to educational opportunity (see, among others, Anyon, 1981; Apple & Weis, 1986; McRobbie, 1978; Rist, 1970, 1978; Tomlinson, 1982; Willis, 1977). To say that humane treatment and education of children who have severe disabilities did not begin until the 20th century is an understatement. Long before children with severe disabilities were understood, accepted, protected and educated, they had to cope with survival in a world where they were put to death, tortured, ignored, hidden away, exploited, and pitied (Hewett & Forness, 1974; Morgan, 1987). Today, unfortunately, they remain categorized.

A general foundation for understanding the historical and theoretical development of special education for children with severe disabilities as it developed in America is traced through three phases. The first phase, however, requires that we leave the context of education and contemporary American society to review a history of attitudes toward and the treatment of individuals with disabilities in the Early Period prior to 1800. The second phase, spanning nearly 150 years, marks the Formative Years of American Special Education. This period begins around the turn of the 19th century when interest in the education of "mental defectives" ignited in Europe and spread to America. This era includes the emergence of behavioristic psychology and its significant impact on the field. The formative period continues through the mid 1940s when a post-war impetus gave way to special interest in the problems of individuals with severe disabilities and in attacking the issue of mental retardation. The third phase in the development of special education for children who have severe disabilities proceeds from the 1960s to the present and is distinguished by a recent emphasis on legislation and litigation, advocacy, and normalization.

Following a brief historical journey of the development of special education for children who have severe disabilities, the next section of Chapter II provides a discussion of two major theoretical views that

have primarily dictated the approaches used to educate this population of children. The final section articulates recent debates that call for a re-examination and reorganization of the field of special education.

Evolution of Special Education for Children Who Have Severe Disabilities

Early Period (Prior to 1800)

Anderson, Greer, & Rich (1982) tell us that throughout most of history little is known about the treatment of children with severe disabilities. Because severe disabilities often occur in conjunction with medical and physical disabilities, it is assumed that many of these children did not live past infancy. Anderson et al. (1982) maintain that in primitive societies the primary goal of human beings was survival. The abandonment or deliberate killing of children with severe impairment appears to have been a common practice. During the Greek and Roman Periods, the practice of exposure and infanticide threatened the existence of children with disabilities (Durant, 1966). As Hippocrates spoke out to challenge the assumption that mental impairment was a result of the anger of the gods, Plato, his contemporary, advocated family care for persons with mental illness. The philosopher, however, supported isolation of children born with defects recommending that they "be hidden away, in some appropriate manner, that must be kept secret" (Cornford, 1945 p.107).

With the onset of the Middle Ages survival became less of a concern, and as society separated into levels (lords, clergy, and peasants), persons with disabilities were commonly ridiculed. Superstitions and myths developed. Persons with intellectual impairment were exalted as "heavenly infants" and exploited by royalty as court jestures (Wallin, 1955). As religion became a dominant force in this period, monasteries and asylums became places of refuge for persons with disabilities and attempts at primitive medical treatment were made (Hewett & Forness, 1974; Wallin, 1955).

The 16th century was a period of religious persecution influenced by hysteria generated by witchcraft. The treatment of persons with disabilities, particularly mental impairment was extremely cruel and inhumane and justified as a means of driving out the evil. During the 17th century the beginnings of special techniques for teaching individuals with vision and hearing impairments were ushered in as well as attempts to describe intellectual impairment (and mental illness) from a more psychological and educational point of view (Hilliard, 1965; Patton, 1986).

The Industrial Revolution brought many children, including those with disabilities, into factories as unskilled laborers where they were abused and suffered high mortality rates (Durant & Durant, 1965). By the close of

the 18th century, schools for children with visual and hearing impairments appeared; little was done, however, for the child with physical and mental disabilities (Pritchard, 1963).

The Formative Years (1800s-1940s)

Scheerenberger's (1982) review of the history of mental retardation points out that throughout history opposing voices spoke out to understand the causes of mental impairment, and, at times, to provide care and training. Around the turn of the 19th century notable advances were achieved by a French physician, Itard, and his colleague, Seguin. Itard's documentation of his work with Victor, "the wild boy of Aveyron," was the beginning of the development of special education procedures based on observation and study (Wallin, 1955). Itard's (1894/1962) published memoirs produced far-reaching effects and, according to Blatt (1987), "may have been the single most important event in the creation of what is now viewed as a genuine field" (p.34).

Seguin, who worked briefly with Itard prior to his death in 1838 and was inspired by Itard's work with Victor, immigrated to the United States in 1848 and had tremendous influence on the creation of facilities and educational programs for individuals with intellectual impairment in this country (Scheerenberger, 1982; Talbot, 1964). Talbot (1964) summarizes that Seguin's landmark contribution to

special education was pedagogy based on combining previously isolated medical, physiological, and philosophical principles with emphasis on the individual as a whole. He introduced music and the use of art media as well as the use of child-originated materials. Seguin reflected the belief "that even the most defective child has some spark of understanding upon which learning could be built" (Talbot, 1964, p.15).

Howe, an American physician, who saw Seguin's particular method of teaching as a way to restore individuals with disability to normal functioning, was assisted by Seguin in establishing the first institution for persons with mental impairment. As a consequence, during the 19th century large state institutions became the primary means of service delivery in this country and abroad. Wolfensberger (1976) maintains that an optimistic philosophy--strongly influenced by the efforts of these pioneering physicians--prevailed at the outset and some individuals with mental impairment were, in fact, successfully educated and returned to their home communities. The optimism sparked by Itard, Seguin and Howe diminished, however, with the eugenics movement and the notion of fixed intelligence (Hewett & Forness, 1974). State institutions came to be viewed as custodial rather than educational; a view that extends to the present (Heward & Orlansky, 1988). Initially referred to as

asylums for the feebleminded, institutions later came to be called hospitals, state schools, and training centers. Despite the change in nomenclature, education and training was usually not provided to the individuals with severe disabilities living in institutions (Heward & Orlansky, 1988).

Special schools for children with disabilities began to appear in 1818, and by 1890 state responsibility for the care of individuals with intellectual impairment was accepted. Special classes appeared in public schools in America toward the turn of the century (Blatt, 1987; Scheerenberger, 1982).

The early 20th century saw scientific approaches applied to the measurement of individual differences by Binet and the formulation of theories of learning by Pavlov and Watson. In the early 1900s Binet's testing movement resulted in state institutions being modified to include work colonies. During this period, Freudian psychology came into being, emphasizing the inner life of the child and the critical periods of emotional development during the early years. In the 1920s and 1930s, the field of medicine began investigating Down Syndrome, endocrine disorders, and brain injury at birth as they relate to mental impairment. The Depression and World War II impeded progress in all fields of special education but, by the late 1940s, the demands of parents and professionals and

federal, state, and private funding gave new impetus to progress in the areas of mental retardation. (Blatt 1987; Hewett & Forness, 1974; Scheerenberger, 1983).

The Era of Legislation, National Support, and Full Inclusion (1950s to Present)

A significant era unfolded in special education in the United States in the 1950s when a series of federal legislation provisions established grants for research and training of personnel in the education of persons with disabilities. President Kennedy's efforts in 1961 notably committed the country's resources to the cause of individuals with disabilities in general and to those with mental retardation in particular (Scheerenberger, 1983). Children with severe disabilities, however, remained totally excluded from public education in the United States, systematically rejected because they were considered to be too disabled to learn (Children's Defense Fund, 1974; Donder & York, 1984; Preamble, P.L. 94-142, 1975; Sarason & Doris, 1979). The concept of educating these children in regular public schools was an outgrowth of the civil rights movement, strongly influenced especially by the landmark case of *Brown v. Board of Education* (1954). The Brown decision, which declared that education must be made available to *all* children on equal terms, was used as the basis for cases brought by parents and other advocates dissatisfied with school procedures that resulted in the segregation of children with

disabilities or the denial of educational programs to them. Litigation particularly significant to this population was the case of *Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania* (1972), a class action suit that established the right to free public education to all children with mental impairment. Prior to this litigation many states had laws allowing public schools to deny educational services to children with severe disabilities assumed to be too disabled to learn. In the same year *Mills v. Board of Education of the District of Columbia* established the right of every child to an equal opportunity for education, declaring that lack of funds was not an acceptable excuse for lack of educational opportunity. Zettel and Ballard (1982) note that by 1975, the right-to-education principle "had been irrefutably established by case law in an overwhelming majority of the states" (p.14). It was then that Congress passed P.L. 94-142, the Education for All Handicapped Children Act (EAHCA). This landmark legislation, referred to as the "Educational Bill of Rights" for students who have severe disabilities, guarantees them access to public education (Ballard, Ramirez, & Weintraub, 1982). EAHCA mandates that all children regardless of the severity of their disability, have the right to a free, appropriate public education in the least restrictive environment and are protected by due process procedures. The law provides five

fundamental educational rights to children who have severe disabilities: the right to nondiscriminatory testing, evaluation and placement procedures; the right to an appropriate education; the right to a free education; the right to be educated in the least restrictive environment (LRE); and the right to procedural due process. Additionally, the law gives priority to identifying and serving children who have been unserved or underserved--a provision that clearly applies to children who have severe disabilities.

EACHA has a sound social component reflected in critical social and political values that emerged during the civil rights movement. The beliefs and social values inherent in the law are outlined by Lehr and Brown (1984) as follows:

> 1) the belief that education makes a difference in a person's life; 2) the belief that handicapped children can profit from an education appropriate to their capacities; 3) the belief in equity; that is in equal educational opportunity; 4) the belief in the value of an education for all people--the universality of education; 5) the belief that governmental benefits should not be parcelled out on a basis of unalterable characteristics of the recipients; 6) the belief in the essential sameness of all persons; and 7) the belief that people should treat each other fairly and decently and that government should deal fairly and decently with the governed. (p.51)

Other cases have since upheld the rights of children who have severe disabilities to receive a free, appropriate education: *Armstrong v. Kline* (1979) and *Battle v. Commonwealth* (1980) established the right of some children

with severe disabilities to an extension of the 180-day public school year; *Department of Education v. Katherine D.* (1984) ordered that a homebound instructional program for a child with multiple health impairments did not meet the least restrictive environment standard; and *Irving Independent School District v. Tatro* (1984) ruled that catheterization and related medical services were necessary for a child with physical disabilities to be placed in a class with nondisabled children.

Since it was passed by the U.S. Congress in 1975 and fully implemented in 1980, EACHA has undergone significant changes. In 1986 with the passage of P.L. 99-457, the provision of special education services has been extended to infants and toddlers with disabilities. More recently, on October 30, 1990, President Bush signed a new law amending EACHA and renaming it the Individuals with Disabilities Education Act (IDEA) to emphasize that people, including children are the focus of the legislation. In addition, all references to handicapped children were changed to "children with disabilities" to place emphasis on the children rather than the disabilities (see Chapter I). The new special education law puts emphasis on meeting the needs of minorities with disabilities, improving personnel recruitment and retention, and advancing early intervention services. It also mandates that schools help students with disabilities plan for when they leave school

and authorizes a one-time grant program aimed at improving transition services.

Having briefly traced the origins of special education for children who have severe disabilities, I turn to a discussion of the two major theoretical viewpoints that have primarily guided instruction for these students and follow with current debates aimed at re-examination and reorganization of the field.

The Progression of Instructional Approaches

Two psychological schools of thought, one associated with the works of B.F. Skinner and the other with that of Jean Piaget, have primarily dominated scientific thinking about the nature of development or behavioral change. Though neither of these theorists were involved in working with individuals who have disabilities, their works have profoundly affected the way that children with severe disabilities are being taught.

Skinner's operant conditioning follows Descartes' "man as machine" model and describes behavior in terms of a one-to-one relationship occurring between environmental stimuli and behavioral responses, with the individual, consequently, being viewed as passive (Skinner, 1953). This view that human behavior results from some environmental action provides the basis of traditional behaviorism and reinforcement theory that dominates education for children who have severe disabilities. It is

a mechanistic approach that considers forces initiating behavioral change to be external to the individual; thus, development is not a consequence of internally mediated restructuring. From this viewpoint, the same principles govern behavioral change in all organisms, and complex behaviors result from linkages occurring among less complex behaviors (chaining). It implies that development is essentially quantitative and continuous since complex behavior represents an accumulation of more and varied responses.

Skinner's operant model focuses on learning that is heavily dependent on reinforcement and is best expressed in the behavioral model of instruction. Applied behavior analysis is translated into structure, precision, and systematic instruction for children who have severe disabilities. Environmental events are systematically arranged to produce desired changes in behavior (Cooper, Heron, & Heward, 1987). Operant instructional procedures have been documented to be effective teaching approaches for children who have severe disabilities (see, among others, Azrin & Foxx, 1971; Dunst, Cuishing, & Vance, 1985; Goetz, Gee, & Sailor, 1985; Hanson & Hanline, 1985; Snell, Haughton, & Lewis, 1987; Utley, Duncan, Strain, & Scanlon, 1983). Many of these authors point out, however, that

difficulties of these procedures include skill generalization and contextual relevance.

In contrast to mechanistic theory, which is best illustrated in Skinner's operant model, Piaget's cognitive-developmental theory expresses the organismic viewpoint. Piaget's Hierarchical Stages of Cognitive Development portrays the individual as dependent on both internal and external factors for her or his development. She or he is intrinsically driven to develop in certain directions given appropriate environmental experiences. The theory details how the student constructs reality--by looking, listening, and manipulating and by modifying, combining, and inventing new schemes. Consequently, this model considers development as initiating from within the individual. It regards the individual as instrumental in bringing about her or his development as she or he actively reaches out to make contact with the environment and, in so doing, generates new experiences that are subsequently used to restructure earlier and less complex behaviors. Development reflects a series of sequential stages, with each stage of development being unique, and development described by qualitative changes in behavior (Piaget, 1954).

It seems as though we may have missed his point, for Piaget's cognitive-developmental theory as applied in special education, rather than emphasizing the inner

goal-directedness and inner mean-making of the approach tends to focus on the so-called mental or developmental ages of children with severe disabilities. To that end, the approach has come under criticism from scholars in the field. Brown (1987) tells us that the model "assumes that those sequences of behavior typical of nonhandicapped students are relevant for the student with severe or profound handicaps" (p.43). Ludlow & Sobsey (1984) warn that strict reliance on a developmental approach may lead to an emphasis on teaching prerequisite skills that are not really essential for later steps. In addition, Bellamy & Wilcox (1982) specify that holding to a developmental approach may perpetuate the perception of students who have severe disabilities as eternal children. Freagon (1982) offers a thoughtful critique of the approach:

> When instructional activities are based on mental, language and social, and gross and fine motor ages, severely handicapped students rarely, if ever, gain more than 1 or 2 developmental years over the entire course of their educational experience. Therefore, 18-year-old students are relegated to performing infant or preschool or elementary nonhandicapped student activities. They are never seen as ready to engage in 18-year-old activities....little, if any, empirical evidence exists to support the notion that severely handicapped students need to learn and grow along the same lines and growth patterns as do nonhandicapped students in order to achieve the same goal of education. (p.10)

Moving away from more traditional approaches, general principles of special education programs today are concerned with functionality, chronological age appropriateness, subsequent environments, interaction with

nondisabled peers, and futures planning directed assisting individuals in acquiring skills and behaviors that will enable them to be as independent in the community and productive as possible after they leave school (See, among others, Guess & Siegel-Causey, 1988; Heward & Orlansky, 1988). Despite the recent shift in focus, the linear sequential ordering of skills and systematic precision in teaching children who have severe disabilities continues to dominate instructional practices. Such practices include precise behavioral objectives, task analysis, and teaching techniques such as forward and backward chaining, and cuing and prompting the child to make the desired response continue to dominate instructional practices. Snell (1983) tells us, "Stated as an assumption and a well-documented fact, behavioral principles are almost universally applied with the severely handicapped as the method of choice" (p. 78-79).

Re-Visioning Special Education

Contemporary scholars in the broader context of regular education are challenging educators to press beyond the confines of existing educational institutions, to explore alternatives to education outside the realm of traditional practice, to examine the assumptions on which our system of schooling is grounded, and to change those assumptions that prove incompatible with true education. (see, among others, Apple, 1986; Apple & Weis, 1986;

Aronowitz & Giroux, 1985; Carnoy & Levin, 1985; Giroux, 1981; Gramsci, 1971; Hall, 1985). Tomlinson (1982) widens the debate to include special education, asserting that the past and present forms that special education has taken are products of particular interests in society. She observes:

> One of the most noticeable characteristics of special education has been power struggles between medical, psychological and educational personnel, who all have an interest in dominating definitions of special education. Existing historical accounts of special education tend to leave out notions of conflict, vested interests and consideration of the wider social motives and expediency which dictated that a special education system should emerge. (p. 27)

Accordingly, a movement within the field of special education questions the appropriateness and scope of the mechanistic paradigm that dominates the field and pushes for an alternative holistic paradigm.

Because this study is directed toward understanding how curriculum has affected the life of a child who has severe disabilities, the remainder of this chapter focuses on both sides of the paradigm debate. The dialogue begins with a glance at a historical perspective of the dominant world view of reality.

Historical Perspective of the Dominant World View of Reality

Heshusius (1989) asserts that two major views of reality have alternately dominated certain periods in history for centuries: the holistic and the mechanistic. They have not only guided the sciences, but virtually every

major discipline in ways of thinking, perceiving, and acting. The major view which has dominated Western thought for three centuries is grounded in Isaac Newton's vision of a stable and ordered universe. Key assumptions of what is often referred to as the Newtonian mechanistic paradigm lie in the positivistic view that the nature of reality is objective, is reductionistic, consists of components, is understood through a mathematical number system, and can be known with certainty with the gathering of sufficient data.

The notion of a stable, simple mathematically ordered universe was the dominant paradigm governing the world view of reality until the quantum revolution of the 20th century shattered this notion with the discovery of unstable, chaotic, non-linear changes in the state of the electron (Heisenberg, 1971). Physics, the field responsible for its origin, and mathematics have abandoned the mechanistic model and turned to a model of "natural chaotic systems" as the view of reality (Hofstadter, 1985).

Quantum physics has produced a turning point in mathematics and science that is causing scientists and philosophers of science to question increasingly the restrictive boundaries of the Newtonian mechanistic view (see Berman, 1984; Bernstein, 1983; Capra, 1982; Leshan and Margenau, 1982; and Prigogine and Stengers, 1984). Heshusius (1989) points out that literature is emerging that describes its influence on other disciplines as well

(e.g. Capra, 1982 [economy and ecology]; Fox, 1983 [religion]; Frye, 1981; LeShan and Margenau, 1982 [art, humanities, and ethics]; Lewis, 1983; [politics and economics]). Scholars in the field of education are aligning with this growing number of critics of the Newtonian Mechanistic paradigm to advocate a shift toward the alternative holistic paradigm that dominated the world view of reality before Newtonian physics and was resurrected with the revolutionary discoveries in quantum physics.

Arguments Supporting an Alternative View of Reality

In the field of education, Doll (1988) develops the critical link between the mechanistic model and the curriculum in American schools:

> In terms of curriculum, this mechanistic view of Newton and classical science has carried over to the cause-effect, stimulus-reaction notions of behavioral psychology; over to the atomistic and reductionist units into which the K-12 curriculum is broken; and over to the linear sequencing and behavioral language in which curriculum is developed and delivered. The current curriculum of behavioral objectives, performance accountability, and effective teaching is essentially, if not predominantly, a curriculum of quantitative measurement and linear ordering. (p. 123)

Referring to the measured curriculum as a "modern day reincarnation of the seventeenth century's view of stability and order," Doll (1988, p. 123) calls for an alternative curriculum that goes "beyond behavioral objectives, beyond linear ordering, beyond preset procedures, beyond stability" (p.126). Drawing on Schon,

Prigogine, and Piaget, Doll offers his conception of a "transformative curriculum" so named for its focus on dynamic, interactive qualitative changes that teachers as well as students go through as they engage in learning. Curriculum is no longer defined "as a preset order which precedes instruction, but as *the process we engage in when we teach and learn with our students*" (p. 130) [italics added]. The most important aspect of the process is the qualitative changes at bifurcation points where irreversible transformations take place and new vistas for learning emerge. In contrast to the present "measured" curriculum, which is incremental and linear, a transformative curriculum is developmental or spiral punctuated by spurts, plateaus and regressions of internal levels of competence. It is neither stable nor pre-set with goals; it is open to change, emergent from interaction, and filled with dialogue.

Doll (in press) points out that evaluation takes on new meaning in a transformative curriculum. Rather than grades and standardized tests, which are lost are in an open, self-generating network of increasingly complex relations, evaluation becomes essentially a negotiary process. The teacher plays a central role in the process but is not the exclusive evaluator. Evaluation is recursive, communal, and interactive, used as feedback in the process of private doing and public critiqueing.

The Three R's of "Readin', 'Ritin', and 'Rithmetic" that characterize traditional curriculum are replaced in a transformative curriculum by Doll's (in press) four R's of Richness, Recursion, Relations and Rigor: *Richness* refers to the depth of the curriculum, to its layers of meaning, to its multiple possibilities of interpretations; *Recursion* denotes the "recursive reflection" of having thoughts loop back on themselves, which lies at the heart of a transformative curriculum; *Relations* refer to the emphasis on pedagogical and cultural connections for meaningful, interactive dialogues; *Rigor* is redefined as combining the complexity of indeterminacy with the hermeneutics of interpretation.

Corresponding to Doll's call for a reconceptualization of curriculum is a push to move the field of special education beyond mechanistic theory, practice and research. Blatt (1977) advocates an open educational system with alternatives; Hammill (1980) criticizes the mechanistic model and points out the resistance to change within the profession regardless of the inadequacies of the model; Chaplin (1979) denounces the remediation approach in special education; Mitchell (1980) raises the issue of professional mechanistic mentality; Fisher and Rizzo (1974) relate the mechanistic paradigm to special education; Poplin (1984, 1985) and Rhodes & Dudley-Marling (1988) support a holistic view of learning disabilities;

Hasselbriis (1982), Leigh (1980), and McNutt (1984) advocate a holistic approach to language; Stainback and Stainback (1984) and Iano (1986) argue for qualitative research in the field; and Stainback and Stainback (1987) criticize the dual system of education and advocate educating all students in regular education.

In an seminal treatise Heshusius (1989) cuts through the confusion of recent literature in the field of special education to rename theories as paradigms, which she argues only creates an illusion of change, and situates the field of special education within the Newtonian paradigm that is undergoing change across the sciences and social sciences. In an analysis of the assumptions about the nature of reality and the nature of knowledge claims that underlie Newtonian mechanistic thought in relation to special education, Heshusius maintains:

1. The Newtonian mechanistic paradigm points to the belief in "simplicity" as the foundation of the paradigm (p. 404). Complexity is broken down into sequentially arranged components translated into practice as task analysis, isolated skill training, mastery learning, programmed materials, and behavioral objectives.

2. Quantification, with the emergence of mechanistic thought, becomes "the" epistemological way to make valid knowledge claims (p. 404). Quantification is translated into measuring and ranking that permeates the special

education field, the never ending search for objectivity, causality, and certainty in diagnoses and categorization of exceptionalities.

3. The machine metaphor is blatantly acknowledged, particularly in the form of behavioral objectives. Short-term behavioral objectives are written in a fashion that produces a machine-like quality of the human being. An example by Thurman & Widerstrom (cited in Heshusius, 1989, p. 406) illustrates this point: "Given Susie with her coat on and the verbal command 'take off your coat,' Susie will grab one edge of the coat at the chest within 10 seconds 5 out of 5 times for 3 consecutive days."

Heshusius (1989) argues for an alternative special education model, one that is grounded in the beliefs that (a) learning is understanding relations rather than pieces of knowledge, (b) the process is transformative rather than additive and incremental, (c) there is no one best way to teach or assess, (d) assessment focuses on what students do over time in engagements purposeful to the student in natural, interactive settings, and (e) possibilities and choices are essential in a curriculum for human learning (p. 142).

Arts and the Humanities

Corresponding with the current turbulence concerning the validity of traditional assumptions of the dominant mechanistic world view is a "call for the humanities and

arts to take their place alongside science in the formal study of human behavior" (Heshusius, 1989, p. 405). The separation that exists between the arts and humanities on the one hand and the sciences on the other is perceived by critics as prohibiting a fuller understanding of reality (Bernstein, 1983; Capra, 1982; Kuhn, 1970; Morgan, 1983). Heshusius (1988) points out that art forms that bridge the separation between formal/theoretical and intuitive/tacit understanding of the world are what Nobel Prize winner Prigogine believes to be the symbol for the 20th century science. The author maintains that including the arts and humanities in special education can "restore the importance of recognizing and justifying appropriate values *as a way of knowing*" (p. 63). To that end, Heshusius proposes that "educators might gain a fuller and more integrated concept of the humanness of exceptional persons and their relationships" (1988, p. 63) through the arts and humanities.

Arguments Opposed to an Alternative Holistic Paradigm

A recurrent theme in the arguments of those who oppose a shift from mechanistic to holistic special education and research base their arguments primarily on the contention that the mechanistic or technical paradigm now in place is capable of addressing and fulfilling the promises of a holistic paradigm (Carnine, 1987; Kronick, 1990; Licht & Torgesen, 1989). Some argue that all is needed is to

combine the assumptions of previous and current models of instruction and inquiry (Gersten, 1992; Lloyd, 1987; Torgesen, 1986). Others downplay the differences between the two paradigms as either not substantial, only a different terminology (Carnine, 1987), or merely attitudinal (Kimball & Heron, 1988).

Kronick (1990) refers to a holistic approach as "concept dense and content light" (p. 8) and argues that the model is insufficient to ensure mastery of skills. Expressing a lack of faith in students to learn from a self-regulating approach, Kronick argues that the approach would limit students to the constraints of their knowledge. A similar distrust is expressed in the ability of teachers to engage in a holistic approach to teaching. "Today's teachers," according to Kronick, "are ill-equipped to ground the concepts they teach in larger conceptual issues or to afford their students ownership and efficacy" (p. 6).

Another argument levied against holistic education and inquiry centers on accountability. According to Ulman and Rosenberg (1986), accountability not based on measurable instructional objectives "becomes a matter of mere opinion" (p. 460). Letting go of mechanistic education practices, they warn us, would cause a collapse into nothingness. It undermines accountability for educational outcomes and can be used to support arguments that IEPs are a waste of time; thus, funds for social services can be slashed, "leaving

advocates of appropriate education for all children defenseless" (Ulman & Rosenberg, 1986, p. 460).

Forness and Kavale (1987, p. 50), in regard to educational research, acknowledge that "the old ways are simply not working." They contend, however, that holistic educational inquiry is anti-science, and propose a position that requires the level of aspirations for scientific inquiry to be lowered. They further suggest training of "special education engineers" to design and implement assessment and intervention strategies based on research as an avenue to improve professional practice.

Other arguments point to the success of mechanistic technical methods in teaching students who have disabilities. For example, Kronick (1990) argues that these methods have been successful in teaching socially acceptable behaviors to students who have disabilities. Similar arguments by Lloyd (1987) and Carnine (1987) partly overlap on the point of technical teaching and research that has flourished in teaching children who have severe disabilities. In an aggressive defense of the technical model of research to guide special education inquiry, Carnine (1987) argues that a holistic or qualitative process does not always fit because interviews, at times, are impossible. To illustrate his point, the author presents an example of "an aggressive, severely handicapped individual with minimal verbal skills" (p.42).

Before leaving a discussion of the arguments levied against a holistic approach to teaching and inquiry, it is significant to this study that Iano's (1987) response to Carnine be elaborated. Iano maintains that it is the area of the "severely disabled" that technical, or behaviorist, research and systems most need to be questioned. He argues that the approach has achieved its predominance in work with individuals who have severe disabilities by default rather than by healthy competition with other approaches. Iano points out that the success of conditioning techniques and the domination of behavior ideology have obscured basic issues and questions, some of which include the following: Are the present techniques that predominate the only or primary way to teach individuals who have severe disabilities? Do the concepts of education and teaching have a place or a special meaning in work with those who have severe disabilities? To what extent should the purposes and interests of typical individuals in their environment take precedence over the interests of individuals who have severe disabilities? Do we ever need to be concerned with spontaneous expressions of interest and developing inclinations of individuals with severe disabilities? Do we ever need to be concerned with the development of understanding rather than imitation or conditioning?

The principles of a holistic approach and an alternative transformative curriculum will be revisited in Chapter VII. For now, I turn to a discussion of the life history method of research.

CHAPTER III

THE LIFE HISTORY APPROACH

> *Whether recorded in the extremity of personal or cultural annihilation, or in the midst of joy and productivity, the anthropological life history offers a positive moral opportunity to pass on stories that might otherwise never be told.*
> *--Langness & Frank (1988, p. 136)*

The life history approach, an integral part of anthropology since the 1920s, is experiencing a regrowth of professional interest in a movement Langness and Frank (1988) refer to as "person-centered" ethnography. The approach is unique in that it becomes a way in which the reality experienced by persons of subgroups in culture and context is directly conveyed.

Life history as defined by Watson and Watson-Franke (1985) is a retrospective account of an individual's life "that has been elicited or prompted by another person" (p. 2). It is seen from the point of view of the person in her or his current situation trying to make sense of her or his relationship to past events. In recounting the past, things that were once important to the person may not be remembered or chosen to be emphasized.

The Autobiographical Method

The life history approach, in conveying the reality experienced by significant "others" in society, goes beyond merely allowing the voices to speak for themselves and

requires additional lucid interpretation (Watson & Watson-Franke, 1985; Langness & Frank, 1988). Therefore, what is heard in life history is not the solo voice of the person whose life it illuminates but what Langness and Frank describe as "two voices singing different versions of the same melody" (p. 96).

The interpretative elucidation required of life history seems to be accomplished ideally through the researcher's autobiographical experience, which Pinar (1988) refers to as "the autobiographical method" (pp. 148-151). Rather than a form of literature, this method is a mode of consciousness through which a reflexive grasp of problematic qualities of situations is captured by the unity of self and situation (Earle, 1977; Pinar, 1988). Pinar (1988) maintains that a focused, sensitive, conscious attunement to the "underlife" of a situation required of the autobiographical method to record the "lived" experience avoids a serious pitfall of qualitative research: restatement of obvious and mundane events, behavior, and words. Pinar tells us, "In its extreme formulation, truth itself lies in the relation of self to situation, knower to known, in the [autobiographical] mode of consciousness which allows the situation to articulate itself, allows the qualitative to surface, the problematic to be resolved" (p. 150). The task of the method, according to Pinar, is *not* to control or to merely portray

the basic meaning of the movement of human life, but *to contribute to the formation of human history* [italics added]. The autobiographical method with the promise that it holds for understanding the reality of situations is employed in this study to probe beyond obvious events, observable behaviors, and mere words to uncover the meaning of Joy's lived experiences. An attempt is made in this study to be explicit about how she experiences the events in her life and the intentions of her parents, other relatives, family friends, physicians, teachers, school administrators, and others and the spirit behind their roles.

Advantages of Life History Approach

A significant strength of life history over other research designs is the holistic nature of the approach. Seeing the individual as a whole, functioning in the larger context of his or her life, rather than piecemeal examination of a person's life removed from context, is one of the most consistent arguments for the use of life histories (Langness & Frank, 1988). Langness and Frank (1988) acknowledge that, in truth, a researcher can never understand an individual "wholly," but maintain that there is merit in the attempt, for it permits an understanding of aspects of behavior and action that would not otherwise make sense. Life histories, as a means by which an individual who has disabilities can be studied holistically

through time in their various roles as family members, students, and clients of the delivery systems, "create composite portraits of them that are far more complete than the profiles suggested by test scores, questionnaires, and ordinary interview" (Whittmore, Koegel, & Langness, 1986, p. 10).

A second strength of the life history approach evolves from its holistic nature. The insider's view that it provides is not otherwise obtained (Whittmore et al., 1986). Edgerton and Bercovice (1976) stress that if normalization is to be taken seriously, we need to listen when persons who have disabilities tell us about their lives. This opinion is also voiced by a man with disabilities who expresses it this way: "You gotta try to see things from my side, too. I know people are trying to do good, but they don't know what it's like to be me!" (Edgerton, 1984a, p. 30). Examining the world in depth from the inside view of another person to "convey directly the reality that [others] experience" is the precise goal of life history research (Langness & Frank, 1988, p. 1).

A third significant advantage of the life history approach is that it appears ideally appropriate for studies of persons who have disabilities as it offers "the best means of getting at the complex relationships of motivations and actions and norms and beliefs" (Aberle, 1951, p. 2). Observations and participation in the daily

events of the respondent's life is more likely to yield valid and reliable information about persons who have disabilities. By concentrating on incidents that either facilitate or hinder a "normal" life-style for persons who have disabilities, Edgerton and Langness (1978) maintain that life history researchers are able to better uncover and understand the process involved in an individual's adjustment to her or his cultural milieu. The holistic nature of the approach, which views individuals within the larger sociocultural context of their lives and over time, requires an examination of the operation and interaction of several concurrent dimensions. Life history research, therefore, illuminates cultural and social facts and not just individual lives or personalities (Langness & Frank, 1988). Langness and Levine (1986) examined a collection of life histories and discovered common themes among the lives of persons who have mild and moderate disabilities. Commonalities discovered in the lives of these individuals included deficits in enculturative experiences which resulted in social incompetence, lives open to the scrutiny of others, disruptions of the normal life course and maturation, stigmatizing effects of labeling and loss of self esteem, and the meaning of developmental disabilities in our society. Equally important to the similarities discovered in the lives of these individuals, however, was the unique differences in the ways that each responded to

her or his situations. This discovery led the authors to conclude that "mentally retarded persons are enormously complex in their personalities, behaviors, and abilities...[and] are anything but a homogeneous group best characterized as an IQ range" (Langness & Levine, 1986, p. xiv). Consequently, the life history focus is important not only for the common themes it uncovers in the lives of persons who have disabilities but also for the diversity of the individuals that it reveals.

The diversity of persons who have disabilities is often distorted by the media in hyped portrayals that depict them as pathetic cripples. Consider, for example, telethons that are demeaning and create false images in the minds of the viewing public. Representations of persons who have disabilities as heroic cripples is likewise a distortion of the reality of their lives. Recent Hollywood movie productions are an indication that the movie industry may be moving closer to portraying the reality of the lives of persons who have disabilities (e.g., *Mask*, *Rain Man*, *My Left Foot*). A young man who has Down Syndrome cast as a regular in the popular television series *Life Goes On* is an indication that the television industry is likewise progressing in its portrayal of persons who have disabilities. In contrast to the movies mentioned that feature nondisabled actors who portray persons who have disabilities, in this television series one of the main

actors has a disability. Although it appears in this case that the industry is making strides in depicting the reality of the lives of persons who have disabilities, this could be a countermarch. A closer analysis reveals that Chris Burke, who is cast in the role of an adolescent, is actually a twenty-five-year-old young adult. Tampering with and rearranging the lives of persons who have disabilities to make them entertaining obscures the realities of their real-life worlds and reinforces society's disabling attitudes. It can be argued that actors are routinely cast in roles of younger or older characters, but for actors who have disabilities, the cost seems too great. It places a focus on "mental age" rather than chronological age and, borrowing an expression from Wolfensberger (1972), contributes to an image of individuals who have disabilities as "eternal children." Such portrayals may actually inhibit the normalization of the lives of persons who have disabilities and minimize the importance of age-appropriate living, work, and leisure.

Burke's character, "Corky," has, among many contributions, raised consciousness about the integration of students who have mild disabilities. Consider, however, the unique contribution of a realistically age-appropriate role for Burke in terms of the light it could shed on the demands of the young adult life of a person who has disabilities. Despite federal legislation aimed at

nondiscriminatory employment, the presence of persons who have disabilities is astonishingly less visible in the work place than in our schools. Many young adults who have disabilities are left floundering after completion of school with little more than an option for sheltered workshop employment. Realistic roles that depict transition from school to work, including decisions that young adults must make related to residence and issues regarding work selection, income maintenance, independent socialization, and altered family relationships, would perhaps enhance the normalization of their lives. The importance of realistic roles cannot be overstated as we move forward to fully implement the American's with Disabilities Act (P.L. 101-336). This legislation, which was signed into law July 26, 1990, prohibits discrimination based on disabilities in the areas of employment, public services, transportation, public accommodations, and telecommunications. It requires all affected entities to provide "reasonable accommodation" to persons with disabilities

In contrast to media portrayals, which often distort reality, another strength of the life history approach is the fact that examination of accurate and detailed descriptions of particular life histories can enormously expand our perspectives of persons who have disabilities. Autobiograpical and biographical literature has emerged as

persons who have diabilities, most of whom were once residents of institutions for "the retarded" come forth to tell their stories (see, among others, Carrillo, Corbett, & Lewis 1982; Parker, 1982; Stephenson, 1983; Williams & Schoultz, 1982). Two recently published works provide insight into the remarkable abilities of persons who have severe multiple disabilities. *Under the Eye of the Clock: The Life Story of Christopher Nolan* tells about the life of an adolescent boy who can neither speak nor control his limb movements. Nolan, who was brain damaged at birth, describes his locked world in a tone utterly free of self pity and regret by striking keys on a typewriter with a pointer attached to his head (Nolan, 1989).

Another equally absorbing autobiography is that of Ruth Sienkiewicz-Mercer. Like Nolan, Sienkiewicz-Mercer can neither speak nor control her limb movements, but it is her story that deserves elaboration. Lacking the head control required to type with a pointer attached to her head, Sienkiewicz-Mercer is more severely physically impaired than is Nolan. Her story, *I Raise My Eyes to Say Yes* (1989) is told with the collaboration of her friend, Steven Kaplan. Using word boards and an interpreter, Sienkiewicz-Mercer communicates her impressions by signaling "yes," "no," and "maybe" with a limited physical repertoire of facial expressions:

> A curled lip and a frown means no, and is usually accompanied by a slight raising of her forearms. The

> more pronounced the curl of her lip, the more emphatic the negative. Raised eyes indicate yes, often punctuated with a smile. Mercer frequently growls, coos, sighs, chirps, yelps, chortles, or even chatters her teeth to add tone to her pronouncements. She indicates maybe with a relatively bland hybrid of her basic yes and no modes. (Sienkiewicz-Mercer & Kaplan, 1989, p. ix)

In describing the general public's reaction to Sienkiewicz-Mercer, Kaplan states that most persons "look past, simplistically dismissing her as a tragedy on wheels...relegat[ing] her to a subhuman twilight zone, sufficiently out of mind if not out of sight" (1989, p. xxv). Kaplan asserts, however, that both the label and attitude are grossly inaccurate.

Skeptics who never read *I Raise My Eyes to Say Yes* or only read parts of it may criticize the work as fiction. Read in its entirety, however, the story interpreted by Kaplan is convincingly Sienkiewicz-Mercer's alone, shaped through her interactions with Kaplan.

Sienkiewicz-Mercer lived in an institution sixteen years and was considered by the staff to be mentally incompetent, and thus was routinely ignored. Kaplan reports that it took him only a few conversations with Ruth to appreciate that despite her severe disabilities, she is a thoughtful, sensitive, and exceptionally bright individual. "This isn't just some cute, energetic little cripple who signals yes and no like a trained seal" (Sienkiewicz-Mercer & Kaplan, 1989, p. xiii).

The reader is impressed not only with Sienkiewicz-Mercer but also her co-author, who has an interesting background. Kaplan is not a professional in the disabilities field with a vested interest in co-authoring the book to legitimize a unique expertise. Neither does he appear to be one who is eager to sell a "sensational" story for capital gain. Simply stated, Kaplan is Sienkiewicz-Mercer's friend. He first worked with her and began helping to write her life story when he was a graduate student pursuing a master's degree in English. Nine years later at the completion of the text, Kaplan is the father of three children and a practicing attorney in Hartford, Connecticut.

Kaplan's work with Sienkiewicz-Mercer is monumental in that it compares to Anne Sullivan's work with Helen Keller; whereas Sullivan released an inner voice imprisoned in darkness and silence, Kaplan released an inner voice trapped inside a functionally useless body. His acute sensitivity to the most obscure of Sienkiewicz-Mercer's responses allowed her voice to be heard and her story to be told. Doubtless there are powerful lessons to be learned from the many trapped voices waiting to be released from others who have severe disabilities. In research, it is a qualitative methodology that allows these voices to be heard.

Methods

Three dynamic qualitative research methods were employed in this life history study to gather data: in-depth, unstructured interviewing, participant observation, and document analysis (Edgerton & Langness, 1978; Langness & Frank, 1988). Stainback and Stainback (1984) maintain that in qualitative research unstructured interviewing is the best way to learn about the perceptions of others. In unstructured interviewing the researcher does not know in advance what relevant questions to ask. These questions emerge from the interaction process in which the researcher becomes sensitized to what is meaningful to the respondents.

In the interviews conducted during the course of this life history study, topics of discussion were be raised by the respondents themselves. The interviewing was recursive in that what was said was used to determine or define further questioning that broadened and deepened the knowledge base (Schwartz & Jacobs, 1979).

The second method for collecting data for this study, participant observation, is defined by Taylor and Bogdan (1984) as "research that involves social interaction between the researcher and informants in the milieu of the latter, during which data are systematically and unobtrusively collected" (p. 15). Such interaction was important for the information it generated about Joy, her

social and physical surroundings, and her activities which were or were not consistent with the information provided in IEPs and unstructured interviews. Participant observation not only confirmed the reliability or unreliability of previous information, but it also filled in the details of events and allowed me to construct Joy's life history from a more expansive and thorough knowledge base than that acquired through document analysis and unstructured interviews.

A third technique used for gathering information about Joy's life was the analysis of documents from outside sources. Reviews of files of agencies providing services to Joy and interviews of persons who know her well or have specific information to offer concerning events or experiences in her life were conducted. A critical source of data included school documents: IEPs, multidisciplinary evaluation reports, data collection sheets, staffing reports, school newsletters, personal correspondence, and Teacher Handbooks. In addition, photographs, video tapes, and newspaper articles, were examined. Comparisons were made between reports by the respondents and related outside sources to provide alternative perspectives and depth to the study.

Data Analysis

The interpretive analysis required of life history research began in the early stages of this study and

continued throughout. By studying field notes and transcripts, I isolated potential emerging themes which were explored through further data collection. Tentative theories were revised on the basis of new information (Glaser & Strauss, 1967). In order for the research to remain focused on themes and concepts relevant to my theoretical concerns regarding special education, analysis constituted an integral part of the data collection process.

Analysis became more formal as the study developed. Conclusions which were supported by the data were either "discounted" or interpreted in the context in which they were collected (Taylor & Bogdan, 1984). Conclusions that withstood this scrutiny were presented with methodological and contextual explanations to readers who may make their own judgments about the validity and relevance of the findings. Having presented the methods used in this life history study, an explanatory note about the difficulties of conducting this research with persons who have severe disabilities is in order at this point.

Difficulties of Qualitative Research Methods

Qualitative research such as the life history study is a longitudinal approach dealing with the growth and change of an individual over a period of years; consequently, a difficulty the researcher encounters is the amount of time in the field required to gather data. To learn about the

life of a person, in depth, in detail, and in the words and activities of that person is time consuming. The discovery of meanings that allow the researcher to understand the complexity of another individual demands participation over a significant duration of the informant's life. In addition, the arduous tasks required in the intensification of perception--noticing the details one never saw before--framing them, ordering them, and giving them names are typically more time consuming and thought provoking than the numerical tasks of counting and ranking that characterize traditional empirical studies.

Since Edgerton's pioneering study, *The Cloak of Competence*, (1967) introduced longitudinal and qualitative research centered on the lives of adults who have developmental disabilities, life history research is increasingly being used with that population (see Langness & Levine, 1986; Bogdan & Taylor, 1982). Edgerton (1984b) acknowledges that despite the growing body of life history research in the field of developmental disabilities, it is limited in scope, amount, and location. This is particularly true for studies of persons who have severe disabilities. The scarcity of life history research of this population is perhaps due less to the low incidence of this population than to the difficulties researchers encounter in managing to learn the perspectives of these individuals who most often are unable to articulate their

responses. Rather than discouraging the application of qualitative research methods to study the lives of persons who have severe disabilities, these difficulties should challenge and inspire the researcher to create new ways of interpreting the perceptions of individuals who are nonverbal. As Biklen and Moseley (1988) stress, "for the nonverbal person the researcher must find other windows on the soul" (p. 160).

This investigation attempts to interpret Joy's perception of self, contextually situated across her educational experiences beginning with her infant and preschool programs and extending through her elementary program. Because she is essentially nonverbal with the exception of a few words and phrases, understanding the meanings that Joy makes of the conditions of her life requires, to borrow Biklen and Mosely's (1988) phrase, "bending the parameters of academic research guidelines" (p. 161). A hermeneutical approach, as described in Chapter VII, is employed in this study to explore possible meanings of Joy's interactions and interpretations of her concept of self.

Respondents

Biklen & and Moseley (1988) suggest that if researchers want to study the lives of persons who have severe disabilities and limited use of language, an empathetic understanding is achieved through participant observation

of the persons in settings where they live as well as in-depth interviews with people connected to the individual who has disabilities. Rather than studying the perspectives of the person who has disabilities directly, the researcher studies their worlds. Although this study attempts to understand Joy's perception of her situations, in order to present a comprehensible account of her life, it was necessary that I draw from the perspectives of those persons most closely connected to her--her parents. The views of others in her life, including her grandparents, teachers, therapists, and paraprofessionals also contributed significantly to this study.

Procedure

Protection of Human Rights

The protection of Joy's human rights was of critical importance. The purpose of the research was explained to her parents and was discussed openly in response to questions during interviews. Diane and Richard Hamilton signed a Release of Confidential Information Form for each secondary source, and no secondary source was contacted until this release is obtained.

During data collection the Hamiltons, extended family members, and significant others who were interviewed were asked to verify information and perceptions. This process continued throughout the writing of the study. The Hamiltons reviewed the completed study and discussed it

with me in detail. They were pleased with the final writing, but had mixed feelings about seeing the project come to an end. On the one hand they were excited that Joy's story had finally been written. On the other hand, they were saddened that the frequency of our contacts will perhaps wane with the completion of the study.

Although Dianne and Richard Hamilton preferred full disclosure of Joy's and their identities, to protect the identities of others participating in this study, I chose to use pseudonyms for individuals, schools, the residential institution, hospitals and specific geographic locations.

Access

Gaining access to Joy's current classroom at Evansville Special School although fairly easy, took weeks to complete. The Hamiltons spoke informally with Joy's teacher, explaining that they were interested in having Joy participate in the research. Next, Baylor District School Board procedures for research to be conducted in its schools were followed. A letter briefly describing the research project along with a consent form signed by the Hamiltons was sent to the Assistant Superintendent for Curriculum and Instruction, who forwarded the request to the research committee. Subsequently, the Director of Special Education and I received written notification of the committee's approval.

Having acquired parental consent and formal school board approval to conduct a study of the life history of Joy Hamilton, a proposal was submitted for official university sanction.

Participant Observation

Participant observations at Evansville Special School were conducted an average of two each week for four months ranging from a minimum of ninety minutes to a full school day. A total of 103 hours of observations spanned 15 weeks. My observations of Joy began in her classroom and extended into the hallways, the music room, the speech therapy room, the adapted physical education building, the bus loading dock, the school entrance, and the conference room. While I accompanied Joy as she went about her daily activities, I kept minimal notes and relied instead on the video camera to record Joy's responses. Even though the camera may be considered an obtrusive tool, it was necessary to record the indepth, close attention to Joy's responses for intense, minutely detailed descriptions of her reactions (see Blatt, Ozolins, & McNally, 1979; English, 1988).

Despite my obvious advocacy for Joy, I avoided directly intervening in her special education program since I did not want to mold her responses. I also felt that rapport with the principal and Joy's teacher depended heavily upon my observing without trying to impose my

beliefs or ideas on Joy's current situation. My moral and professional obligations to Joy eventually took precedence over discomfort that intervening may strain my relations with the professionals closest to the research or compromise the objectivity of my research. When Joy's teacher, Maria Lopez, repeated that she had exhausted all possibilities, referred to Joy as "a mystery" and asked for suggestions that I may have to enhance her program, my ethical obligation to be as human as possible required an honest, well-thought response (see Chapter VI). Another researcher's conclusions regarding a similar dilemma he encountered when researching the life of a person with mild intellectual disabilities seemed appropriate:

> Maybe nobody ever will have the understanding that you have of this person and their situation, and maybe nobody ever will be in a role to make constructive change. And if you don't grasp the opportunity, its going to be lost. But you only feel the obligation if there *is* a close relationship. If there's not, then you don't have the same sense of obligation to do something, or to add your perspective. But it's because there's a close relationship that there's an expectation that I will be involved in these discussions..., and were I not to do so, I wouldn't be upholding my part of the bargain, in *their* minds. They wouldn't ever understand it if I said, "I can't give you my opinion. I'm supposed to be an objective bystander." That just wouldn't cut it. (Cited in Frank, 1980, p.11)

Interviews

The Hamiltons live nearly a two-hour drive from the immediate area; therefore, distance was a factor that impeded the frequency of indepth, open-ended interviews.

Following verbal accounts of the details of Joy's first two years, which were videotaped for later reference, the Hamiltons were interviewed at least once every two weeks for six months in telephone conference calls. Topics in the interviews were raised by the Hamiltons. As I became familiar with Joy's present situation, I directed questions toward topics her parents raised in order to clarify information or ascertain its relative importance to them. After several months direct questions relating to themes of interest were raised. In general, however, the content of interviews was determined by the Hamiltons.

Portions of videotaped interviews that pertained to Joy were transcribed verbatim with accompanying comments regarding the context of the interview, my impressions during the interview, and notations regarding the relation to information gleaned from other sources. A log was kept of each meeting, telephone call, or informal contact with the Hamiltons and secondary respondents (teaching staff, school directors, nurses, extended family, etc.) This record allowed me to check carefully the context of information during the later stages of analysis.

Document Analysis

In addition to data collected from interviews and participant observation, analysis of related documents provided supplemental information about the life of Joy. Among the most useful documents examined were (a) Joy's

special education records from the Baylor District School Board (IEPs, multidisciplinary evaluation reports, progress reports, and data collection sheets), (b) records from her infant intervention program, (c) medical records from the NICU, (d) medical, social, psychological and habilitation reports from JTS (residential facility), (e) family and school videotapes of special occasions and events, (f) school documents including teacher and parent handbooks and newsletters, (g) family photograph albums, and (h) newspaper articles about Johnston Special School in the city newspaper as well as articles about Joy in her family's hometown newspaper.

These documents were analyzed at different levels to examine both intended notices and the more subtle messages (Bogdan & Biklen, 1982). The school newsletters are a good example. Although several newsletters from Johnston Special School were among the personal documents of the Hamiltons, there were no newsletters from Evansville. Diane explained, "We never got anything like that from them. Nothing that would let us know what was happening. All we ever got was a few notes from her teacher and Joy's IEPs." Therefore, I requested copies of the Evansville newsletter from the school specifying issues from the period Joy was enrolled there, from 1988 to 1990. I was informed that copies from the previous year, 1988-1989, were not available. Two newsletters, one dated February

1990 and the other dated April 1990 were forwarded to me; newsletters that were printed after my fieldwork began at the school.

Each nine weeks reporting period a school newsletter from the staff at Johnston Special School was mailed to the parents. Although it was designed primarily for the parents, some of the information contained in the newsletters was for the school district and the community in general. The format of each issue was fairly consistent: a message from the principal; news from each classroom, each therapist, and the adaptive physical education teacher with highlighted activities or skills that each child was engaged in learning and her or his progress; recognition of those who visited the classrooms, including parents, extended family, and friends; mention of children who were having birthdays; details of upcoming field trips and social events; a brief personal profile of a faculty member which addressed her or his professional accomplishments but included information regarding the individual's family, personal accomplishments, community involvement and special interests as well; and announcements concerning workshops and inservices attended by the professional and paraprofessional staffs.

The Evansville Special School parent newsletter, which I was told is issued monthly, has a similar format: a message from the principal; announcements concerning

community events; announcements concerning staff members; information about upcoming events at the school; news from each classroom; and announcements from the adapted physical education department.

There is, however, an audible silence in the Evansville newsletters. Although two former students who have physical disabilities are mentioned by name in the April 1990 issue, the progress and accomplishments of the "significant others," the children who have severe multiple and intellectual disabilities go unnoticed. Other silent voices include those of the related service personnel, the therapists whose services ordinarily are a critical component of the children's programs, and the paraprofessionals, who are an extension of the classroom teacher's eyes and hands. Both school newsletters are used to communicate news about the school, the children, and the staff to the parents and the community. Less obvious, the newsletters become an expression of the inner life of the schools. By attending more to temporal matters such as dates for meetings, testing, IEP conferences, and the school calendar, the staff at Evansville reveal an overriding concern for control and management. Once these announcements are made, various children are recognized. On the other hand, Johnston Special School's primary goal was recognition of the children, with secondary aims to encourage parental involvement, to recognize staff, and to

facilitate staff support. Interest in individual children was manifested in descriptions of each one's progress. Each child was recognized at least once and even the smallest steps, the most minute signs of progress, were reported positively. Although Joy's name does not appear in either of the Evansville newsletters, she was recognized several times throughout each issue of the Johnston newsletter. Recognition of the diversity of the children and those who worked with them, parental involvement, and the unspoken message that all children mattered are principles that seem to have powerfully influenced the life of Johnston Special School.

Exit

Ultimately, a study of Joy's life would culminate at a saturation point (Bogdan & Biklen, 1982; Taylor & Bogdan, 1984). However, Goetz and Lecompte (1984) remind us that data collection usually ends not because the sources of information have been depleted but because of the exhaustion of time, energy, and forbearance.

A major transition occurred in Joy's life as she approached eight years of age. According to admission requirements at JTS, Joy was discharged from the institution and transferred to another facility. Since Joy was placed in another residential facility located in the state where her parents live and over 200 miles from the immediate area, the study necessarily concluded with her

transfer. However, I attended the Individual Habilitation Plan (IHP) and IEP conference for Joy held a few weeks after she was transferred. When it was explained to the Hamiltons that it was not possible to have Joy attend school in the community or be with typical children part of the day because she was assigned to the "Total Care Team," this situation presented a new set of challenges in the study of her life. Considering also that her special education program was reduced from 5 1/2 hours to 1 1/2 hours, and the facility staff refused to incorporate "choice" in Joy's IEP or IHP, I recognized that Joy's life history could be centered on other issues. But, a distance of 200 miles is not easily accessible. I realized too, that the enormous amount of information from my firsthand experience in her preschool program and the rich data I collected from the time I spent in her classroom at Evansville was more than a sufficient base for the study. Although lured by the new possibilities, I necessarily chose to conclude this study following an in-depth examination of the first eight years of Joy's life that spans more than two years in the field (considering the time I served as principal of her preschool program), and months examining volumious professional and personal documents, copious field notes, and transcribed interviews and videotaped school experiences.

Analysis and Interpretation

In life history research, data analysis is not a definite stage that always follows data collection. Although Glaser and Strauss (1967) maintain that analysis begins when the researcher enters the field and continues throughout the study, for me, analysis began in the preliminary stages before entering the field. My decision to pursue this line of research, a life history approach, was, for me, an analytical process. In qualitative research, the process of analysis is ongoing, dynamic, and data based. Its key aspects are focus-finding, coding, and generating more abstract themes.

Focus-Finding

One of the qualitative researcher's first task of analysis is to create a focus for the study (Geer, 1964). Peshkin (1986) stresses that *The* most important focus of a study does not exist. Therefore, rather than discovering *The* focus, focus-finding is an evolutionary process during which a focus emerges because the researcher, by choice and decision, gives it importance and meaning (Sutton, 1987). Although my original interest was in Joy's special education programs, as I acquired information and interpreted it, I redirected and expanded the focus of her life history several times throughout the course of the study. For example, as the story of her life unfolded and I probed into the events surrounding her birth and her

family's on-going dilemma, I discovered that for a child who has severe disabilities, the conception of a transformative curriculum must not begin when the child enters school. Rather, it must originate in the hospital with the infant educator as a member of the hospital support team. To that end, my focus shifted from a conception of a transformation curriculum limited primarily to the classroom to exploring its application across many environments and all phases of Joy's life.

Coding and Evolution of Themes

To be able to manage the volume of data collected, I found it necessary to begin by physically sorting the materials into stacks and folders according to sequences and transitions in Joy's life. Since my focus was on her special education programs, there were three major transitions in Joy's life related to special education when she entered into relations with a new set of people and acquired a new self-conception. The transitions, or significant turnings (Mandelbaum, 1973), in Joy's life were used as a starting point to sort the data included, (a) infant intervention, (b) residential special school, and (c) community special school. A fourth category, tomorrow and beyond, was added later. IEPs, evaluation reports, progress notes, medical reports, field notes, transcripts of videotapes, newspaper articles, photographs and other

documents were filed chronologically according the process codes [passages in Joy's life (see Bogdan & Biklen, 1982)].

As the data guided the study in new directions, the coding categories were revised and the data compiled using a more focused approach. Because I was interested in analyzing the differences in Joy's special education programs within the framework of my theoretical concerns about the field, special education data was recoded according to twenty categories (see Appendix A for a listing of coding categories). From the revised codes I read and reread the data to "see" links and comparisons and similarities and differences that emerged as patterns. Through interpreting and integrating patterns, I attempted to generate themes at a more abstract level (see Chapter VII for a discussion of themes).

Generating Meaning

To facilitate analytic, generative thinking, Bogdan and Biklen (1982) urge qualitative researchers to think of what emerging patterns remind them. Similarly, Taylor & Bodgan (1984) tell us, "One often stumbles across some insight that ties everything together only after a prolonged period of time in the field" (p. 67). As I reflected on Joy's preschool program at JTS Special School, holistic tenets espoused by Heshusius combined with the concept of a transformative curriculum, as described by Doll (1988) created the link to understanding the

differences in her preschool program compared to her present program. Therefore, aspects of the program at JTS Special School that point to evidences of a transformative approach in teaching children who have severe disabilities were examined. Although the staff at JTS Special School had no awareness at the time that the attitudes and beliefs that influenced their decisions reflected holistic tenets and subtle shadings of a transformative approach, a glance back at Joy's preschool program reveals that elements of the approach were seemingly interwoven within the philosophy and practices that guided the program, (see Chapters V & VII).

The concept of a transformative curriculum was used to help organize my thinking, not just generate it. The more salient features of Joy's special education program as well as the less noticeable practices were related to the approach. At the same time, I attempted to point out those aspects of her programs which characterized the more traditional mechanistic approach. The resulting study, which combines my experiences as a special educator and a student of curriculum studies, interprets and integrates a reconceptualization of curriculum for children who have severe disabilities within the broader context of a movement to reconceptualize curriculum. Revisiting the features of the alternative approach proposed by Doll (1988) we are reminded that the term *curriculum* takes on

new meaning. Rather than a pre-set order which precedes instruction, curriculum is redefined as "the process we engage in when we teach and learn with our students" (p. 130). In contrast to the "measured" curriculum, a transformative curriculum is open to change, filled with dialogue, not pre-set with goals, and emergent from interaction. Progressing counter to the linear and incremental sequencing of the measured curriculum, a transformative curriculum evolves in a developmental or spiral continuum punctuated by spurts, plateaus, and regressions of internal levels of competence. It is a process that takes inner goal-directedness and inner mean-making to be the primary characteristics of learning. Learning is viewed as a self-organizing construction of relations which occurs at bifurcation points where irreversible transformations take place and new vistas for learning emerge.

Impressions

Langness and Frank (1988) tell us that "a life history, unlike a biography or an autobiography, is always a delicate and *collaborative* venture. Thus the outcome--the life history itself--is the result of a dual input from two individuals with their own past experiences, biases, interests, needs, and motives" (p. 61). To underscore the collaborative role of the researcher, Richardson (cited in Langness & Frank, 1988, pp. 100, 136) offers the metaphor,

"The Myth Teller." Here myth as defined by Webster (1981) is a "traditional story to unfold part of the world view of a people or explain a practice, belief, or natural phenomenon" (p. 755). (It does not mean an ill-founded belief, something fabricated, or not based on factual history.) Richardson uses the metaphor to accentuate that the researcher and informant are basically two human beings who meet each other in daily existence and together encounter the reality of being human, each telling their version of "the human myth." For me, "myth teller" is an electrifying term to describe the collaborative role of the researcher. It captures the inner thresholds of passage, the deep life experiences in the search for meaning and significance.

The life history approach, according to Langness and Frank (1988), offers a unique crucial moment to pass on stories that might otherwise never be told. As it cuts across cultural and political ideologies and reveals what is essential about the human condition, the reader hears the voice of the researcher putting her or him "in touch with the experiences, thoughts, and feelings of another's life" (p. 88). It is a research approach that holds within it tremendous power for developing the human potential of those who use it. "Call it 'negotiation,' 'an encounter,' 'interaction,' or 'an exchange'--the collaboration that takes place in the best of life-history work can be for the

informant, researcher, and reader a transformative experience" (Langness and Frank, 1988, p. 5). The researcher can never be the same afterwards. It teaches one to focus, to be patient, to be reflexive, to listen, to continually select. It forces the researcher to pay attention to people in a different way. It is humanizing. It is art. It is passionate with an explosion of feeling; one can actually feel inner value, the rapture of being alive.

CHAPTER IV

JOY' S BIRTH AND INFANT INTERVENTION PROGRAM

We were a young, married couple starting our family, and our first child was born with a birth defect. You think of this happening to someone else, not you.

--Diane Hamilton (see p. 135)

Historical Context

When Joy was born the summer of 1982, school systems were undergoing radical changes across the United States. With the passage of P.L 94-142, the Education for All Handicapped Children Act (EAHCA) in 1975, schools in the South, to ensure the flow of federal funds and to keep step with other regions of the country, were gearing up to provide programs for all children, regardless of the severity of their disabilities.

Historically children with severe disabilities were institutionalized either in the hope that there was some chance of improvement or to relieve the burden of care from their families (Friedberger, 1981). With the passage of EAHCA some of the children living in institutions were brought home to live and to attend public school in their communities. In addition, parents of younger preschool children with severe disabilities were beginning to receive support services to prevent institutionalization later. Corresponding to these dramatic changes in American society was legislation which was being introduced to significantly

alter the existence of residential facilities for persons who have severe disabilities. In light of this historical context, what factors led to Joy's placement in a residential facility during her formative years? The answer lies in understanding her parents, Diane and Robert Hamilton, the circumstances of her birth, the experiences of her first two years of life, and the influence of significant others in her life.

Her Parents' Courtship and Marriage

On a fall day in 1979 in a small, rural community of southern Tennessee, Diane Burke, a junior in high school, met Robert Hamilton, a high school senior, when she and other members of the school choir sold mugs on the front steps of the school. In the confusion of the event, Diane caught a glimpse of a tall, lean, dark-haired student who was making his way through the crowd toward her. In a soft-spoken voice Robert asked Diane what she was selling, and, as Diane puts it, they began "making eyes." As he purchased one of the mugs from Diane, he introduced himself, then asked for her phone number. Later that week he called her and asked her for a date.

Diane and Robert continue to tell their story.

> Diane: We dated for awhile but the last 2 or 3 months it seemed we were just arguin' all the time. There was lots of peer pressure. We were together too much. The number one problem I'll tell you is that neither of us was committed to the Lord. I realized my life wasn't what it should've been.

> Robert: Sounds different I know in these days, with the world like it is, but Diane and me...we hadn't had anybody else. We were virgins.
>
> Diane: When Robert says, 'Let's get married', I told him we needed to go our own ways and date other people. I knew I loved him, but we just weren't getting along. If it was meant for us to be together, then I felt it would happen. I was a little scared. You see, my very best friend got married--he wasn't even a church goin' man. He left her right after the honeymoon.

They went their separate ways, but as the months passed, Diane reports that she was not happy:

> I had a bum senior year. I wouldn't go back to that time for anything. The boys I dated were silly--it felt so dorky--they were kids saying things they didn't really mean. One night I was talking to one of my girlfriends, and she told me that I was still in love with Robert. His best friend told me that Robert talked about me a lot. I knew we missed each other.

Diane and Robert resumed their relationship and began planning their wedding. According to them, although their parents preferred that they wait to get married, they were not opposed to the marriage. Diane continues, "I was still worried though, 'cause me and Robert didn't go to the same church. Robert's Assembly of God, and I went to the Baptist church." Evelyn, Robert's mother adds, "My daddy told them that should be the least of their worries."

On August 1, 1980, Diane and Robert were married in a small Southern Baptist church in Pineville, Tennessee, where they were both raised. Pineville, a community of nearly 9,000 persons, is supported largely by the forest industry. An enormous paper and plywood mill spans the town's thoroughfare and is the hub of local activity.

Diane's father, Dan, and Robert's father, Wayne, have worked at the mill since they were young men. Diane's mother, Clara, is a teacher at one of the community's three elementary schools, and Evelyn, Robert's mother, is a housewife. With five children to raise, Evelyn provided day care service inside her home for fourteen years, but when her youngest child started to school, she gave up the work to become a full-time homemaker.

Early Married Life

Robert was employed as an assistant manager at Beall's, a department store chain in the South, when he and Diane were married. Diane stayed at home enjoying her new role as homemaker. Having adopted a role more like her mother-in-law than that of her career-oriented mother, Diane became a "homebody," as she puts it, preferring work at home to outside employment. She has on occasion worked as a cashier at the local Wal-Mart store when "money gets tight," but she does not enjoy it. She prefers to "work around the house and do [her] crafts."

As newlyweds Robert and Diane shared their dreams of owning their own home and one day having a family. The hope of owning their own home was realized much sooner than most couples their age. After only eight months of marriage, they moved from the house they were renting into a three-year old home they purchased with a government subsidized loan. A photograph in their family album

depicts the young couple standing proudly at the entrance of their new home. To their right is a wooden plaque inscribed "The Hamiltons--Robert and Diane," which Robert purchased on their three-day honeymoon to Hot Springs, Arkansas. At the bottom edge of the plaque are two eye-hooks to hang additional name plates as their family grew. Earlier photographs reveal that the plaque, a treasured possession signifying their union and family name, was likewise displayed at the entrance to their rented house.

The quaint house, which is where they continue to live today, is attractively trimmed in cedar and painted blue. Its appearance is a pleasing contrast to the brick homes that line the street. With "a little over 900 square feet," as Robert describes it, the house has three small bedrooms, a bath, a living area, and a combination kitchen-dining area. Though the kitchen is not equipped with modern convenient appliances, such as a dishwasher and a disposal, a laundry room is conveniently located near the kitchen and opens onto the one-car carport. The neatly manicured yard has small shrubs and seasonal flowers that frame the exterior of the house and border the walkway. Adorning the front yard is a young plum tree, which Diane and Robert planted several years ago. Their house is located on a quiet street in a well kept working-class

neighborhood and is conveniently located near a community park and recreation center.

They recall having lived in their new home about seven months when Diane learned that she was pregnant. Excited about the prospects of becoming a new parent, yet concerned about the additional financial responsibility, Robert began to seek other employment with higher wages and better benefits. He applied for a position with the fire department and began working there about six weeks before their baby was due.

In preparation for the arrival of their new baby, Diane and Robert set up a nursery in one of the spare bedrooms of their home. Photographs reveal a neatly arranged nursery featuring a crib complete with bedding, a chest of drawers, several plush animals, and juvenile wall hangings over the crib. Two baby showers honoring Diane added to the excitement and anticipation of having a baby..."a new baby girl," Diane says, "I never did think boy, only girl. All Robert and I talked about was a baby girl. All of the baby gifts were for a girl. I had only one boy outfit." One of her showers was hosted by friends at First Assembly of God, the church they continue to attend today. Among the pictures of this shower is a close-up of a gold baby bracelet with a card that reads, "To: Grandbaby from Grandmother and Grandfather [Burke]," who were to become first-time grandparents.

Diane and Robert explained that "a few babies were still being born" at the small hospital in Pineville, but they chose, as did many Pineville residents, to select a hospital outside the immediate area that provided prenatal and delivery services. Franklin General Hospital, located in rural north Mississippi 30 miles from their home in southern Tennessee, performed such services although it is similar in size to the hospital in Pineville. Diane recalls that when she first suspected she was pregnant, she made an appointment to see the obstetrician. He examined her in mid-November, confirmed her pregnancy, and estimated her due date to be July 28. On her first visit to the doctor, Diane says, "I had a little cold and my ears hurt. Mama says I had a rash, but I don't remember it."

Diane and Robert relate that the pregnancy progressed with no complications other than the cold during the first trimester, and regular check-ups revealed normal weight gain. As Diane's silhouette changed, their dreams of having a baby became more of a reality. A photograph of the couple taken during the last trimester reveals them proudly "showing off" Diane's protruding abdomen. Like most couples expecting a baby, they had the usual concerns about the health of their baby, but they approached the birth situation with the expectation that their baby would be normal. There was no history of congenital abnormalities in either of their immediate families. Until

Diane and Robert's baby was born, neither family, the Burke's nor the Hamiltons, had much exposure to individuals with developmental disabilities. According to Diane, the only exception is a great aunt, " who was born premature and weighed only a pound. They said she would be behind...that she may die. Memaw Sanders couldn't take care of her." She adds, however, that her aunt has "a good mind" and eventually earned a college degree.

Joy's Birth Situation

July 28, the due date, passed with no signs of labor. Between 2 and 3 p.m. the following day, however, Robert recalls that he and Diane's mother, Clara, accompanied Diane to the hospital in north Mississippi where the obstetrician confirmed that Diane was on the outskirts of labor. Diane says that she was admitted to the hospital, prepped for delivery, and administered "drip" intravenously to speed the delivery process.

Other relatives and close friends arrived later to await the birth of the Hamilton's new baby, expecting the baby to be born later that night or early morning.

As the night deepened, according to Diane, her labor continued but did not progress. Despite hours of hard labor, her cervix had not dilated beyond three centimeters. Diane recalled:

> The doctor broke my water. And, he pushed and squeezed on my belly. He squeezed hard, as hard as he could to get the water out. Oh, it hurt so bad! I didn't know then that he wasn't supposed to be

> squeezing on me like that. I just thought that was the way it was...you know, to have a baby. Then he checked the baby's heartbeat with the thing around his neck and said that it's heartbeat was "goin' crazy."

Evelyn and Clara recall the doctor telling them at that point that he was going to stop the "drip" because the baby's heartbeat was irregular, and he wanted to give Diane time to rest. It was late into the night. Louise, Evelyn's sister, shares her point of view: "I think the ole doctor was just tired. He wanted to go on home. So, when it [the baby] didn't come to suit him, he just stopped the 'drip'." Clara and Robert stayed with Diane at the hospital through the night.

The next morning, according to Diane, the "drip" was resumed and between 1 and 2 o'clock in the afternoon she was taken to the labor room. At 5:30 p.m. on Friday, July 30, 1982, Joy was born weighing 6 lbs., 11 oz. as Robert observed. "It was a dry birth," according to Diane, one that followed "27 hours of labor." She recalls that gas was administered to her at the moment Joy was born. She does not recall any details of Joy's birth nor does she remember seeing Joy or even being aware her baby was a girl. She refers to the event as being "like a dream." She states, "All I can remember when she was born is that the pain quit. I didn't hurt anymore. Then, they put me out." The experience related by Diane is typical according to Darling and Darling (1982) who argue that the parents' feeling of powerlessness prevails in the labor and delivery

room as a result of strict medical control over the birth situation of an infant with abnormalities. The writers note that, typically, birth "defects are either denied or minimized by professionals in the immediate postpartum situation" (p. 99). Professional denial was demonstrated not only at the moment of Joy's birth but throughout the first hours of her life as discussed later in more detail.

Parental suspicion is often aroused at the moment of the birth of an infant with a visible abnormality. Walker, Thomas, and Russell (1971) and D'Arcy (1968) have noted that unintentional cues by delivery room staff, such as "the look on the nurse's face," consultations in hushed voices, and "nurses who looked at each other and pointed at something" are signals the parents interpret as something is wrong. Consider the cue that aroused Robert's suspicion:

> I was nervous, really nervous. Diane was going through a lot. The doctor asked for the forceps, and the nurse handed them to him. I was sitting behind Diane's head and couldn't see what was happening...but,...(turning his head side-to-side) I'll *never* forget that look, the look on the nurse's face...a funny look, for just a second. I knew something was wrong. I thought maybe the doctor dropped it [the baby]. I didn't know what happened.

The OB nurse assisting in Joy's delivery, June Covington, knew of Robert and Diane. Although she is not a close friend, the Burkes and the Hamiltons have known her for years. As a member of the fire department's emergency medical team, Robert ran into June one day when he was

transporting a patient to the hospital. He mentioned to her that I was conducting a study of Joy's life and would be getting in touch with her. When I contacted Ms. Covington and asked her to share her experience at the time of Joy's birth, she stated, "I don't recall anything about the birth." She added, however, that the Hamiltons are "a real sweet family" and stated that she was one of two nurses assisting the delivery room when Joy was born. Although she continues to work at Franklin Hospital, Ms. Covington stated that she no longer works in OB. When I related the conversation I had with Ms. Covington to the Hamiltons, they were quite surprised. Robert responded, "I wonder why she wouldn't talk about it [Joy's birth]?" He and Diane further stated they understood that Ms. Covington had "a breakdown" related to job stress and was hospitalized in Jackson for several weeks.

The nurse's response to my interview typically represents the influence of hospital routine and medical control over labor and delivery, which parents are expected to accept. Darling and Darling (1982) suggest that "birth is defined as a medical event," and at the time of delivery, "the baby becomes a product of the hospital rather than a product of the parents" (p. 99).

Continuing to address the issue of professional denial, other evidences in the family's accounts of Joy's birth reveal that a cloak of secrecy fell upon the hospital

staff. Although the obstetrician had been communicating with Clara and Evelyn frequently and informing them of his directives, all communication ceased when Joy was born. Shortly after she was delivered, the family was able to see Joy for only a brief moment. Evelyn recalls the event:

> Wayne knew something was wrong. We asked the nurse if we could talk to the doctor before he left. But, he went right out the door in the back. He went right out, and he knew we wanted to talk to him!
>
> Phyllis: Are you sure he knew?
>
> Evelyn: Yes, the nurse went to him after we asked her. He wasn't too far from us. He walked out in a hurry and didn't even speak.

Cunningham and Sloper (1977) note that unusual alterations in normal hospital routines also arouse parental suspicion that something is wrong. Clara's account of the pediatric nurse's actions is perhaps the most poignant evidence of concealment and one which later caused bitterness and resentment:

> The nurse was behind the nursery window. She had Joy wrapped up in a blanket--we could only see her head. She held her just for a moment. We didn't get to see her very long. Then the nurse closed the blinds. She said she was sorry she had to close them, but they were circumcising a baby boy and had to close the window.

When the family learned days later that there were no male infants in the nursery when Joy was born, it added to their anguish.

Cunningham and Sloper (1977) also mention that when parents ask their physicians directly if something is wrong with their babies, problems are often denied. Such was the

case when Joy's family, apprehensive about the shape of her head that appeared squeezed by the forceps, mentioned their concerns to hospital staff. The pediatrician in simple denial reportedly assured Robert that there was nothing to be worried about. As Robert puts it, "He said that everything was all right. He said the baby had been through a lot. She was real sore and just needed rest."

Traditionally, most pediatricians have felt that parents "are not ready" to hear the truth about their baby's defects immediately after birth. When denied the truth at first and then told of the defect several hours or days later, the parents commonly resent the delay (Darling, 1979). Information about a birth injury was not shared with them during the immediate postpartum period. However, Diane and Robert were told of the insult a week later at a conference they requested with the obstetrician. He informed them, as Diane puts it, "Joy was born with a knot in her cord."

Studies indicate that the absence of a truthful, informative diagnosis as soon as possible is the most common complaint of parents about the situation of first information (Cunningham and Sloper, 1977; Darling, 1979; McMichael, 1971). Darling and Darling (1982) point out that another parental preference--that both parents be told together--is often also unfulfilled. Hearing the same information from the start is especially important when

decisions must be made regarding medical treatment. The experience of first information recounted by Diane when she was told about Joy's difficulties typically represents the dilemma posed:

> They [the hospital staff] told everyone to go home. Robert and Mama and Daddy had gone back to Pineville to get some rest, and Evelyn and Wayne went to Columbia to Evelyn's mom's for the night. It was about 11 o'clock (Joy was born at 5:30 p.m.). The light came on in my room. It woke me up, but I was still so groggy...everything was so blurry. A lot of doctors and nurses came in. They said, "Your baby's having complications." The doctor said her breathing wasn't right...she would stop breathing every 2 or 3 minutes. They said they started a IV but needed to send her to Monticello [Medical Center] where she could get special care. He said they [Monticello Neonatal Intensive Care Unit] were sendin' an ambulance to get her, with a special trained nurse. He said he was sendin' a nurse with a form for me to sign. I was so weak and everything was so blurry, I don't see how I could've held the pen. I don't remember doin' it, but I guess I did...sign the paper. I don't remember how I was able to do this either...call my daddy. Somehow I managed. I didn't want to call Robert. He and Mama had been up with me all night the night before. Daddy called Robert, though, and they [her father, mother, and Robert] came back to the hospital. They just got home and in bed when I called. They had to get up, get dressed, and drive all the way back to Franklin.

A number of studies (Drotar, Baskiewicz, Irwin, Kennell & Klaus, 1975; Olshansky, 1962; Solnit & Stark, 1961) describe the parents' initial reactions to being told that their child has a defect as shock, disbelief, grief, loss, helplessness, guilt, disappointment, anger, sorrow, frustration, and anxiety. The first information is so devastatingly painful that it should not be disclosed in

the absence of adequate family support. The situation of Diane's being alone, however, could have seemingly been avoided had the family been given truthful information after Joy's birth. Diane's father, Dan, complained bitterly about the hospital staff's insensitivity and false assurances that led to the impersonal manner in which his daughter was informed about her baby's condition:

> I don't know who the nurse in charge was...but, I feel like she lied to us [referring to the pediatric nurse who closed off the nursery to the family]. When the doctor came in, I told him I didn't appreciate it one bit! I told him, "You let everyone who loves her leave, and you knew she shouldn't be by herself!" I got so mad. I told him, "how would you like it if that was your daughter? Would you want her left alone like that?"

Whereas her memory of some of the incidents surrounding Joy's birth is blurred, one aspect--her father's devotion--remains crystal-clear.

> When Daddy got to the hospital that night he was so mad. He chewed the doctors out. Daddy stayed with me all night--right there in the room. I'll never forget it. He stayed right there...he wouldn't leave my side. Robert and Mama had to go home. They'd been up with me all night the night before. They had to get some rest. But Daddy was there...right there, he wouldn't leave me.

Gabel and Kotch (1981) conclude that the birth of a child with disabilities may affect the child's grandparents by disrupting the typical role grandchildren play in the psychological and emotional development of grandparents. Much is to be learned from the stress, resentment, and frustration grandparents experience when trying to cope

with professional procedures and practices that deny them access to information and support. Evelyn's account of the dilemma that she and Wayne faced when they arrived at Monticello Medical Center typically represents this concern:

> Wayne and I were worn out. We went on down to mother's for the night...it was closer to drive down there than go all the way back to Franklin. We hadn't been sleeping long when the phone rang. Wayne sat straight up! He sat straight up in the bed, I'll never forget it. He said, "I knew it, I knew something was wrong with her" [Joy]. It was Robert. That's when our nightmare began. He said an ambulance was taking the baby to Monticello. We told him we would go straight to the hospital and wait for it. We didn't want Joy to be there alone...with no family. [We went to the emergency room and waited for the ambulance.] When we heard the siren and saw the lights, we got closer to the door [emergency room entrance]. They came busting through the doors...running, not just hurrying, but running as fast as they could with her incubator beside them...gettin' her upstairs as fast as they could. There were tubes everywhere. I saw Joy for just a second. I thought she was dead. She was so tiny and still. I asked the nurse if she was alive, and she said, "Yes, but she's serious." A lot of nurses and doctors were working with her, and we waited for them to tell us something...let us know what was happening. They wouldn't tell us anything. I told them, "Please tell us about her. Her parents can't be here. We're her grandparents and the only ones she has here." But, the doctor wouldn't tell us anything. He said he would only talk to the parents.

Whether to protect confidentiality, to avoid malpractice, or to abide by hospital routines, for whatever reasons, the pediatric neonatologist reportedly chose not to disclose any information to Evelyn and Wayne regarding Joy's condition.

The ambulance must have arrived at Monticello with Joy sometime after midnight, for medical records reveal that her date of admission was July 31, 1982. From the time she was admitted until 7 a.m. the next morning when Robert arrived at Monticello Medical Center (MMC), information was withheld regarding the infant's condition. For nearly seven crucial hours the baby, it seemed, belonged only to the hospital. The hospital staff controlled the information and made decisions without respect to the needs of Diane and Robert or the extended family.

Robert arrived at MMC around 7 a.m. to sign a release for the doctor to perform "a spinal tap" on Joy. He recalls the doctor telling him that Joy's condition was critical and the next 72 hours were the most crucial. Her chances for survival would increase with the passing of each hour. Robert stated that the physician told him that Joy as having trouble breathing. "She would stop breathing every 2 or 3 minutes. He said if she lived she would have to be in NICU [Neonatal Intensive Care Unit] several weeks. He told me he called other doctors--specialists--to run some more tests."

When a normal baby is born, hospital staff, friends, and relatives offer advice to the new parents. When a baby is born with an abnormality, however, the mother is often isolated on the maternity ward and ignored by those who do

not know how to react to the situation (Darling & Darling, 1982). Diane comments:

> I would lay there in the hospital...I could hear the babies being brought to the rooms, and I couldn't sleep. I cried all the time. [Before they took her,] the ambulance driver and nurse brought Joy to me and let me rub her all over...her arms and legs. But, I was so out of it, I couldn't remember what she looked like. I just wanted out [of the hospital]. I wanted my baby. They gave me a number to call [at MMC] and said I could call anytime...and I did. I couldn't sleep, so I called all night long to see how she was doin'.

Diane was released from the hospital Sunday morning, less than 48 hours after Joy was born. Her parents, Dan and Clara, picked her up at the hospital and enroute to MMC, Clara tried to prepare Diane for what to expect. Diane recalls the event:

> Mama was trying to prepare me for what she looked like...so I wouldn't be upset. Mama said Joy was hooked up to lots of machines. There were tubes everywhere. She had a IV in her head and they were feeding her through a tube in her navel. She told me she didn't want me to be shocked. Before I went in, the nurse said Joy probably wouldn't respond to me. She said Joy was having seizures, and the medicine they were giving her was making her sleep all the time...But, when I saw her, I wasn't shocked. I saw her...touched her...and she opened her eyes! She woke up when I touched her. She was so asleep, but when I rubbed her hand, she woke up. She knew I was there!

Being with Joy on this day held special meaning for Diane. It was her second wedding anniversary. When recounting this moment, Diane said tenderly, "Joy was an anniversary present...a sweet anniversary present."

Diane recalls that she was not allowed to hold Joy until she was two weeks old. The nurses, however, encouraged her to "rub her and talk to her and love her a lot." She and Robert were allowed to visit with Joy for only one hour four times each day. While Joy was in NICU, Diane stayed with Evelyn's mother, Grandmother Pearl, in Columbia, which was only a 20 minute drive from MMC. Between trips to the hospital and throughout the night Diane recalls continuously calling the NICU to check on Joy;

> And the nurses would tell me they were lovin' on her. But, (with a slight chuckle) that made me mad! I didn't like it...you know what I mean? I wanted to be lovin' her myself. She was my baby, not theirs. I'm her Mama. I should be lovin' her, not them. I guess that's kinda silly to feel that way, but that's how I felt! That was the hardest thing...to walk out of ICU without my baby.

Having met Grandmother Pearl one August day in 1991, I recall thinking how much her name fits her, for she is truly a gem. Pearl is a sensitive and thoughtful individual. In recalling Joy's birth, Grandmother Pearl, in her soft-spoken voice offered her view of the situation:

> Pearl: I don't know why (nodding her head negatively) that doctor didn't do a C-section.
>
> Phyllis: Well, Pearl, you've been around a lot longer than us (referring to Evelyn, Diane, Robert, Evelyn's sister, Louise, and myself). Have you ever heard of this happening before? For the "drip" to be stopped when a mother is in labor and to seemingly ignore a problem with the infant's heartbeat?
>
> Pearl: (Nodding her head negatively) No! (straightening her back, sitting taller and leaning

forward in her chair). You get busy in a hurry. You don't wait! He [Diane's doctor] called here the next day after Diane got out of the hospital. He wanted to talk to her, but she had already gone to see Joy. Did you know he was at the hospital [MMC] the next morning after Joy was born talking to the other doctors about the cord?

Phyllis: No, did you see him...did he talk to you?

Pearl: No, but they [Diane, Robert, Evelyn] knew about it. We believe he paid the hospital bill.

Phyllis: What hospital bill?

Evelyn: We believe that he was the one who paid off the hospital bill. A balance of $4,000 was paid anonymously.

Diane: Our hospital and doctor bills were thousands of dollars. After medicaid and insurance paid, we still owed MMC $4,000. They kept hounding us for the money, and we didn't know where we were going to get it. We didn't even have a hundred dollars, let alone thousands! My mom and dad helped us some. They paid some of the bills, but there was no way that we could come up with that kinda money. Me and Robert were so worried. I prayed and prayed. It finally went on our credit record. Medicaid was late paying. They finally turned it over to the collection agency. Our credit was ruined for seven years.

Phyllis: How did you find out that it was paid?

Diane: Well, I called the office where you pay the bills to tell the lady that we didn't have the money and she told me, "the account was taken care of yesterday." She said it was paid and we didn't have a balance.

Phyllis: Did you ask how it was paid? Or who paid it?

Diane: No.

Phyllis: Why not?

Evelyn: It just didn't matter at the time. It was paid and that was the main thing (Diane agrees nodding affirmatively). We didn't want to stir up anything, you know? We were just happy for them it was paid.

Phyllis: I understand, but why do you think it was the doctor who paid it?

Evelyn: Well, this was several months after Joy was born and Diane and Robert had talked to him about the cord. I think he just paid the bill because he knew that Diane and Robert didn't have the money, and he might end up getting sued. Paying the bill cost him a lot less than a law suit. Know what I mean?

Phyllis: But, you don't think that someone else, perhaps someone from your church could have paid it?

Evelyn: No, no...that didn't happen. We would've known.

Diane: They're working people like us. They didn't have $4,000 either. They helped us in lots of ways. They prayed for us, Brother Martin and his wife came up to the hospital, they brought Joy gifts. And, they called to check on us. They came by the house when we got home . But, they didn't pay that bill. We would've known.

Phyllis: How?

Diane: They would've told us. They wouldn't let me and Robert worry about it so much. They would let us know.

Robert: We believe it was him. It couldn't be anyone else.

Then, Pearl looking at me and nodding her head affirmed the family's assumption saying, "That's who *we* believe did it," and the subject was dropped.

My curiosity about Dr. Brown grew following the interview with Pearl. I was interested in knowing more about the physician who delivered Joy. I asked Diane and Robert to tell me more about him, and they began by describing his physical features. They specified that he was "short, with reddish-brown hair and probably in his late thirties today." Then Diane adds,

> We just don't like him. I don't know why (shrugging her shoulders), but we just don't like him. He chewed out a nurse...I don't know what it is...What is it, Robert?
>
> Robert: He doesn't talk to you like most doctors do.
>
> Phyllis: Why did you choose him?
>
> Diane: He was the only one delivering babies at Franklin General, and we didn't want to use the Pineville Clinic. But, there are some people who like him, and some who don't.

They went on to tell me that they heard that Dr. Brown was sued a few months before Joy was born when a patient of his, a young woman, reportedly died. Diane said, "You don't know what to believe, but they say he had alcohol problems." Robert adds, "Other problems, too. We heard he was getting a divorce."

Life in the Neonatal Intensive Care Unit

Evidence reveals how the first few weeks of Joy's life sharply contrasted with that of the typical new born child. Rather than a traditional baby book to record the growth and development of their new baby, a separate photo album was used to trace Joy's first four weeks of life. The album contains page after page of photographs of Robert and Diane in scrub suits holding and caressing Joy. Unlike the usual data in baby books such as the first smile, the first time baby rolled over, the first outing, etc., the "firsts" for Joy were recorded in captions under photographs and included the following events: first time Diane held Joy; first time Diane gave Joy a sponge bath in the NICU

bassinet; first time Diane trimmed Joy's nails; first time Diane and NICU nurse gave Joy a bath; the day Joy was moved from NICU to the nursery in an incubator; the day Joy was moved from an incubator to an open bassinet in the nursery; first time Diane was allowed to dress Joy in baby clothes; the day Joy was moved from the nursery to a private room where Diane was allowed to stay with her; and, the day Robert took Diane and Joy home from the hospital.

Unlike most infants pictured in NICUs that are of low birth weight, the photographs of Joy depict a well nourished infant who seemingly looks out of place with the respirator, tubes, and monitors. She is a pretty baby with large eyes and lots of dark hair. With the exception of indentions on each side of her forehead, which appear to have been caused by the forceps, and an area on the right side of her head that was shaved to insert an IV, Joy's appearance is much like that of a typical newborn infant.

As Diane, Robert, and I reviewed the photographs together, Diane pointed out a picture of Joy that she particularly likes; one of Joy in an incubator with a pink teddy bear at her feet. Diane tenderly described the toy as the "prayer bear" Robert bought for Joy.

Perhaps the most telling evidences of the difficulties of Joy's birth, however, are revealed in what is missing in the photographs on the first page of the photograph album. This page contains pictures taken at Franklin General

Hospital where Joy was born. There are two photographs of Diane lying in the bed before Joy was born and one of her taken after Joy was born. There is a photograph of Robert in a scrub suit standing in front of the nursery window with a caption that reads, "Robert, after Joy was born." Strikingly obvious was that, unlike typical family photographs that mark the occasion of the birth of a baby, the baby was not pictured in these photographs. There were no pictures of Joy; not one of Diane holding her, not one of Robert holding her, not one of the nurse holding her, nor one of Joy in the nursery. The photograph of Robert taken shortly after Joy was born reveals the nursery window in the background with the blinds closed. These photographs strongly support the family's version of the afternoon Joy was born; the baby was quickly whisked out of sight by the hospital staff, the nursery was closed off to the family, a shroud of secrecy fell over the hospital, and family and friends were encouraged to leave the hospital although it was only 6 p.m. in the afternoon.

According to hospital records, Joy remained in NICU 14 days, was transferred to the nursery for 9 days, then moved to a private room for 2 days. The two days in a private room were, according to Diane, "to prepare me for having her home, so I could get used to feeding her and taking care of her before I took her home." Diane commented:

> I was in the bed down here (motions low), and she was way up here (raises her arm to indicate the height of

> the nursery. bassinet) I took her out of there and put her in the bed with me. The nurse came in and said, "Where's the baby?" and I told her, "She's right here" (motioning to her side under her arm). I had her in the bed right beside me. She stayed with me the whole time. She slept right beside me. She was so tiny...so small.

A photograph was taken of Joy wearing a pink baby dress the day she was released from MMC. The caption indicates that the baby dress was also worn by Diane when her mother brought her home from the hospital twenty-one years ago. A caption under another photograph of Joy asleep in an infant carrier at their home precisely sums up Diane's and Robert's feelings that day, "We're finally home."

The Hamilton's quiet, stable private lives were transformed overnight into a hectic, confusing, stressful public exposé. A medical team led by a neonatologist and including a pediatric neurologist, a pediatric cardiologist, a specialized NICU nurse and a social worker met with the Hamiltons occasionally to discuss their findings. Among stacks of medical bills is an 8 page statement from the pathology lab that lists 102 various tests that were administered and another two-page summary of 18 tests administered in radiology. Despite extensive laboratory testing and the expertise of a highly specialized team, it seems that the Hamiltons knew little about the extent of their baby's difficulties. Upon leaving the hospital with Joy, they were told, as Diane

puts it, "Joy had three spots on her brain. The neurologist said, 'It's like a bruise--it takes a long time to heal.' They probably knew then she was brain damaged, but they didn't tell us." Describing Joy's serious conditions with such an understatement made it more difficult to bear the grave news they were told later.

Homecoming

Shainess (1963) and others have suggested that the homecoming of a "normal" baby may trigger a major family crises. Albeit the author's comments are directed at mothers who most often are the significant care takers in the early stages of an infant's life, I believe that fathers are also susceptible to dramatic changes. Shainess states, "Motherhood is a shock, a blow on the head, from which many women never recover. Little in our culture prepares women for the ultimate realities" (146).

Darling and Darling (1982) argue that "our culture romanticizes parenthood, and prospective parents typically expect doll-like infants, nestled in pink or blue blankets, who sleep peacefully in lovingly rocked cradles. Colic, sleepless nights, spitting up, and extra laundry are not part of the fantasy" (117).

Medical records reveal that Joy was discharged from MMC on August 25, 1982, when she was 27 days old. Diane and Robert recall the relief they anticipated as the day approached when Joy was to be released from the hospital.

Diane states, "I just wanted her home with us. We thought when we got her home everything would settle down and our lives would be normal." "But," as Robert puts it, "that was just the beginning of our problems." "Everything from then on was negative," according to Diane. "It was always bad news. We could never hear anything positive."

The financial problems associated with the extra costs of bringing an infant home who has disabilities was a tremendous burden for the Hamiltons. Although the bills for medical care were covered by health insurance, they had difficulty meeting the "hidden costs" of providing for an infant with special needs. Comments by Robert illustrate this point:

> Insurance paid 80% and Joy received a SSI check [Supplemental Security Income], but it was never enough to cover the bills. All of her doctors were 50 miles away, and we had to make trips each week to Monticello for her to see the heart specialist, or the neurologist, or the pediatrician. The extra trips...just paying for the gas and our food was costing us more than we had. Mom helped out by taking Diane and Joy to the doctors so I wouldn't have to miss so much work, but it was still hard for us.

Robert went on to explain that because he changed jobs shortly before Joy was born, his health insurance from his former employer paid most of the medical bills. His insurance premiums with the fire department, however, reportedly more than tripled after Joy was born due to her "pre-existing condition."

Evidence that medical bills were escalating and with every turn, as Diane stated, "all we heard was something

negative," is revealed in a stack of medical bills. Claims filed for the costs of the neurologist were submitted on two occasions, once in February 1983 and again in May 1983. Each time benefits were denied because, as stated on the forms, the "major medical benefit period maximum had been met." The services were also filed on the policy Robert had with the fire department, but were denied once again as an ineligible charge because the services performed were related to a "Pre-Existing Condition." Increased insurance premiums, medical expenses not covered by insurance, and out-of-pocket expenses for routine doctor visits were taking their toll on the Hamilton's modest income.

Shortly after they brought Joy home, Robert recalls that he was required to attend 10 weeks of fire fighters' training in Memphis, which restricted his time at home to weekends only. "He had to go," as Diane puts it. "It was his job. He had to go...but, I always knew though he was in Memphis, his heart was with us...with me and Joy."

Stress related to financial pressures and his absence from home emerged as physical symptoms associated with a nervous stomach that persisted over several months and required Robert to seek medical attention.

A Case of Delayed Diagnosis

It was early November 1982 and Joy was three months old when Diane recalls the event that marked a significant turning in her life.

> We thought everything was fine. We thought she might need some time to "catch up" because I was in labor so long. We had to go somewhere every week...to the pediatrician, the eye doctor, to her heart specialist--she had a heart mummer. Robert was at fire school and I was by myself *again* [Diane's first information about Joy's difficulties was hours after Joy was born when she was alone in the hospital room. Her emphasis here on being alone again implies that she and Rcbert did not receive the news together]. I got my mother-in-law to take me and Joy to her specialist...and, I thought everything was okay. He pulled up a chair. I had Joy right here (indicating her lap) and he put his legs all the way right here (motioning that the doctor sat facing her with his legs straddling her chair) and he just got my hands and he said, "Things are not fine." With tears in his eyes, he says, "Her head is not growing." He says, "There's no other way to put it. I thought it last month, but I just didn't want to say anything--give it another month." But, he says, "Her head should be growing," he says, "It has not changed." Oh, I squalled and squalled...I was so upset. I had to give Joy to Evelyn. She had to handle it by herself. She was asking him the questions and making the decisions and all. He made us an appointment with Dr. Princeton [neurologist] at Monticello before we left.

Diane goes on to explain that the cardiologist stated that he would have to get back with them about the results of the CAT scan which Dr. Princeton ordered that day. Diane vividly recalls the day that the cardiologist phoned to give her the news;

> Cyndi [a friend] came over and we went to eat pizza. When I got home he called and says he had the results of the test, and it showed her head wasn't growing. There's no words to explain how I felt. I squalled. I couldn't stop squalling. I'd hate...I'd hate for you to know how I felt. I said if her life has to be like this, I wish she'd never been born. It's not fair to her to have to live her life like this. But...you get used to that. You go on with it. I called Mama, and she said I had to learn to handle it on my own. But, Evelyn came over. She called Mama and asked her, "Are you going to get Diane?". But, Mama told her I had to handle it on my own. So Evelyn came over.

Impact on the Extended Family: The Grandparents' Perspectives

A conversation with Clara reveals the forces impacting on her life when Joy was born. Diane's younger sister, Janice, who was 4 years old, was having terrible nightmares. As Clara puts it,

> It was having an effect on all of us. We had been in so much turmoil since August. I told Diane, "Joy is your baby. Janice is mine." Janice was having terrible nightmares. She was dreaming that someone was killing us. I've got to get her back in a normal way of life. Diane begged me to stay at night, but I had my family I had to get back to. I told her, "You have to live through this as best you can."

Evelyn also had a young child, a six-year-old son, at home. She remarked that she too had to go on with her life the next day. Her approach to Joy's situation, however, is quite different. Evelyn appears to take a more active role as an advocate for Joy, seemingly visits her more often and frequently participates in planning conferences for Joy.

The importance of grandparents, their feelings, and their ability to support the young family cannot be overstated (Gabel and Kotsch, 1981). Cochran and Brassard (1979) tell us that children who have disabilities have a significant impact on their grandparents. At the same time, grandparents influence the development of handicapped children in their direct interactions with the child and through the support they provide to the parents.

Gabel and Kotsch (1981) observe that the birth of a child with disabilities is a particular kind of crisis-one

that directly affects the grandparents and other members of the extended family as well as the parents. This crisis reverberates throughout the family net work, affecting the relationships among the children, the parents and the extended family.

Grief and anger appear to characterize the mourning responses of Joy's grandparents. Wayne, Robert's father, who sensed "something was wrong" when he first saw Joy, questioned why this was happening to them. Thankful that he and Evelyn had been blessed with five healthy children, "Why us?" was a private thought he often shared with Evelyn. Dan, Diane's father, on the other hand continued to express bitter resentment of hospital routines that led to his daughter's receiving first information about Joy's condition in solitude, without the support of her family. Joy's grandmothers were working through this time of tremendous stress by searching for answers. Clara, Diane's mother, was looking for answers as to what caused Joy's condition. As we talked in the Hamilton's living room on one summer day, Clara specified what she believed to be the cause of Joy's condition. Referring to a book on birth defects that was given to Diane by the NICU nurse, Clara stated:

> They always blamed Dr. Brown. I was completely convinced when I read this book that her condition was caused by Diane's fever and rash. It described Joy's condition to a "T." I told Diane I am as convinced as anything that's what caused Joy to be like she is.

The condition that Clara believes to have caused Joy's disabilities was, as she pointed out, congenital toxoplasmosis, an infection which, if contracted during the first or second month of pregnancy may cause death or serious defects (Carter, 1978). Turning to the page in the book to which Clara referred, is a description which reads,

> [Toxoplasmosis] is not a virus, but a comma-shaped organism that infects many birds and animals as well as human beings. It seldom produces symptoms in an adult, although some individuals do have a feverish illness, occasionally with brief rash, cough, swollen glands or a variety of other, infrequent symptoms. (Apgar & Beck 1972, 106-107)

Recalling that Diane had a rash (which Diane denies) and a slight fever during her first trimester, Clara chooses to believe that Joy's condition was the result of an infection that Diane acquired early in her pregnancy. Carter (1978) states that the infection is caused by a parasite found predominately in the feces of cats. Infections in humans are caused primarily by eating undercooked meat. A study by Alford, Stagno, and Reynolds (1974) (cited in Carter, 1978), revealed that the majority of infants of women who acquire toxoplasmosis during pregnancy are unaffected. Carter (1978) specifies that toxoplasmosis can be diagnosed by screening serum of newborn infants. There is, however, apparently no evidence in at least 102 pathological tests that were administered to Joy when she was in NICU that the parasite was present.

Whereas Clara leans more toward believing that Joy's condition pre-existed before birth, Evelyn is inclined to believe that Joy's condition was the result of a birth injury. She states emphatically:

> I am not as easy on Dr. Brown as Clara is. I believe he should have done a C-section when he knew the baby's heart beat was not right. I hold him responsible. Instead of putting her back on the drip, he should have done something right away. He shouldn't have let her lay there in labor so long.

According to Diane and Robert, Dr. Brown informed them that Joy's difficulties were the result of a knot in her umbilical cord that frequently cut-off circulation perhaps several months before she was born. It appears, however, that this information may not have been passed on to the NICU. A report by the neurologist dated August 2, 1982, three days after Joy was admitted to NICU reads,

> The history of this child has already been recorded in the records of Drs. Barton and Gibbs and appear [*sic*] to be that her delivery was essentially unremarkable with the exception of the use of forceps.

Seeking Help

According to medical records the neurologist confirmed on November 23, 1982, that Joy's head circumference was far below normal limits and recommended that the Hamiltons pursue services of the "Crippled Children's Program" of Tennessee. They were also advised to enroll her in an infant intervention program in Monticello. Twelve days later Joy was evaluated at the Center for Infant Development in West Monticello. A summary of the

evaluation states that according to a developmental test, Joy was functioning about one month below her chronological age on the mental scale and at her chronological age on the motor scale. It was recommended that Joy be seen monthly at the center where her parents would be instructed in ways to help stimulate Joy.

When Joy was 6-months-old, on February 18, 1983, she was seen at the Tennessee Children's Hospital. A social history reveals stress factors in the home as "financial" and "concern for child." Regarding the parent-infant relationship, the social worker filed the following report:

> Mom admits being extremely protective and describes herself that way. Says she's unwilling to leave child with anyone; says child most all the time sleeps with her. Father held child asleep during interview. His interaction, when she was awake, was very good and he was quite attentive. Parents appear extremely concerned about child and probably unrealistic about development now and future expectations...they may be waiting on a miracle???...During interview allowed parents to ventilate about difficulty with hospital surrounding child's birth. They are quite bitter and felt as though they were greatly mistreated.

As Diane gave the report from the Children's Hospital to me, she tearfully stated that she did not know it then, but she must have been in denial and referred to the social worker's comments. Considering, however, that an infant evaluation performed two months prior to the visit with this social worker revealed only a mild delay in Joy's mental functioning, based upon information available to them at that time, the Hamiltons could perhaps have had a fairly balanced perception of Joy's difficulties. Despite

an indication that the Hamiltons were experiencing stress related to financial burdens, to their concern for Joy, and to their treatment by hospital staff when she was born, there was no evidence in the social worker's report of a recommendation for lay support services, counseling, or a referral to community agencies for support.

Office notes from the neurologist reveals that information and records regarding Joy were transferred to the Crippled Children's Hospital. There is an interesting twist in the data regarding Joy's birth when the attending physician at Crippled Children's Hospital records the presenting problem as "[The] product of a very complicated perinatal period with suspected subsequent anoxic injury...."

The Hamiltons returned with Joy to the Crippled Children's Hospital six months later when she was 1-year old. A social/psychological summary completed by the social worker reveals her perception of a conference with the Hamiltons.

> Spoke at great length with parents about child's dev. [*sic*] delays, which they seem to have had difficulty coming to grips with. Mom had lots of questions and both parents were tearful when we were talking about her prognosis and what she would be needing.

At this meeting arrangements were made for the Hamiltons to visit a special program at Louisberg, a small community about 30 miles from Pineville. Diane, recalling how devastating the news was to her that Joy would require

a special program said, "I 'boo-hooed' ...just squalled all the time. I didn't want her in a special school. I wanted her at home with me."

Center-Based Infant Intervention Program

When she was 13-months-old Joy was enrolled at the Louisberg Day School where she received services daily Monday through Friday from 9 a.m. to 3 p.m. Transportation was a problem and making two trips each day to Louisberg was a strain on the family. Elizabeth Moore, the director of the school explained that the school serves ten children ages 1 to 5-years-old who have developmental delays. When Joy attended the school, there were two attendants, a part-time speech therapist who visited once a week, and a part-time occupational therapist who visited the school once each month. Diane described the speech therapist as "our turn-to person." "Every time I wanted to know something, I would ask the speech therapist. I would ask her, "When's Joy gonna sit up?"

Meanwhile, when Joy was 16-months-old Diane and Robert had a healthy baby boy. Daniel, however, was delivered by another obstetrician. Diane stated that she took all of Joy's medical records with her to the doctor's office and fully informed him of the complications she experienced during Joy's birth. Her new obstetrician reportedly assured Diane that he would not allow her to lie there "27

hours in labor." "He told me eight hours is long enough. He would do a C-section."

A headline on the front page of the Laurel News Observer on January 25, 1984, reads, "Laurel Profiles March of Dimes." Under the headline is a large photograph of Robert, Diane, and Joy with the following caption:

> POSTER CHILD-Joy Hamilton, daughter of Robert and Diane Hamilton, Pineville, has been named the 1984 Laurel county poster child for the March of Dimes. For story and other pictures see page 1B of today's Laurel News Observer.

A bold headline on page 1B reads, "Laurel county poster child Joy has experienced rough 18 months," and introduces a four column article describing Joy's first few months of life with an emphasis on the contributions of the March of Dimes, which reportedly provided the initial breathing equipment and special ambulance, as well as various tests and evaluations. Diane is quoted as saying, "We were a young, married couple starting our family and our first child was born with a birth defect. You think of this happening to someone else, not you." The article closes with a summary of the family's experience as expressed by Diane who is paraphrased as saying "that she had always heard that children with birth defects have a special place in a person's heart 'and we never knew what that meant until now.'" (Laurel News Observer, January 25, 1984, 1B).

Other headlines on the page read, "Mother's march to be Sunday," "Louisberg Day School provides assist," and "Support group forms." Interested in knowing more about the support group and whether the Hamiltons participated, I asked them about the article. Robert stated, "There were some people who tried to get one going, but it seems like it never got started."

From January to April Joy seemingly made some progress at Louisberg. A letter to the director, Elizabeth Moore, from the Monticello Center for Infant Development dated February 1984 indicates gains in her social development. Despite the progress she was making at Louisberg, Diane reported that in May, Joy started refusing to eat, began to lose weight, and cried and screamed constantly. Diane describes her dilemma:

> I was going crazy. She was losing weight. Robert would come home every two days [from the fire department] and sleep. I called her pediatrician and he told me he was gonna be gone tomorrow but bring her bags and we'll put her in the hospital the next day. "No, you're going to do it tonight," I told him. "If she can rest, I can rest." Joy was having a fit, buttin' her head against the bed.

Joy was admitted to the hospital that night. Diane stated that the pediatrician called Joy's neurologist who ordered another CAT Scan. The neurologist reportedly was very concerned about Diane's and Robert's health. As Evelyn puts it, "fatigue had taken over." He explained to them that the CAT scan showed water was filling up areas of Joy's brain that were damaged. He reportedly told them, "I

think you need to put her in a school where they can meet her needs. We've got to find a place for her." Diane said that through the tears she asked the physician if he meant an institution. He responded, according to her, by explaining, "These places are not like institutions. They're places where the children are taken care of." He told them he would search for the best possible place for Joy; thus, wheels were placed in motion for Joy to be placed out of her home.

Elizabeth Moore, the director of Louisberg Day School, reports that although Diane was having difficulty with Joy at home, she was not a problem at school. She expressed concern about Diane, for, as she put it, "Diane cried all the time." She described Robert and Diane as "strong Christians. They are like many young couples we see who lose their innocence when they have to face the difficulties of having a handicapped child. They went through a lot together. They are a very sweet couple." Ms. Moore went on to tell me that they "very seldom have children as 'low' as Joy," and explained that they were not prepared to "meet her needs." She indicated that one of the trainers was very attached to Joy and cried when she learned that Joy was going to be institutionalized.

A Case of Professional Dominance: Recommendation for Out-of-Home Placement

According to the director and photographs of Joy taken at Louisberg, she was apparently enjoying her time there.

It seems, however, that despite the progress that others were seeing, a tacit though persuasive message was being sent to her parents: We at Louisberg are not trained to work with children like Joy, and rearing a child like Joy requires coping skills and attitudes that you do not possess; therefore, Joy needs placement in an institution. The most telling evidence of this implicit message is a cherished magazine article given to the Hamiltons by Ms. Moore. "Jenny, is Her' s a Life Worth Living?" (McAlister, 1982) is a personal mini documentary of a couple' s agonizing decision to institutionalize their little girl who has severe disabilities. The story of their dilemma is written by the little girl' s father, a free-lance writer, who conveys the relationship he has with his daughter, Jenny, in simple, yet moving descriptions. Reading the McAlister' s story of Jenny is like reading the Hamilton' s story of Joy. There are striking similarities: Both children are girls; Their names begin with the letter J; Jenny was born in 1972, Joy in 1982; They are the first born child in each family; The girls each have a younger brother; Both families profess a strong Christian faith; Both girls have visual impairments and similar physical impairments; Both Jenny and Joy reportedly had frequent spells of incessant crying, a behavior experts tell us is common for children with damage to the central nervous system (see Bailey & Worley, 1989; Finnie, 1975).

A most unsettling similarity about Jenny's and Joy's situations, however, is that their parents were disempowered in the decision making process. The impetus to institutionalize Jenny as well as Joy did not originate with the girls' parents; the professionals were making the decisions for them. Joy's neurologist was the thrust behind Joy's out-of-home placement, and McAlister tells us, "Without our asking, Jenny was chosen (from a long waiting list) to participate in a program at a total care facility for retarded children" (p.72).

McAlister quotes Biblical scriptures which he and his wife interpret as supporting their decision to place Jenny outside their home. They have reconciled their decision by staying involved and even selling their home and moving near the institution so they can see Jenny daily. "Keeping involved spiritually, emotionally, and physically makes the difference," (p.74) according to McAlister. The McAlisters and the Hamiltons remain closely bonded to their daughters, which is most often an exception. As McAlister puts it,

> some parents abdicate their God-given responsibility for the sake of convenience. We see children every week whose parents have literally deserted them--no visits, no presents, no contacts at all. They are "out of sight, out of mind," never again to be mentioned or fondly remembered. (p.73-74)

McAlister's assertion, however, that parents abandon their children in institutions for the sake of convenience is a half-truth. Many children, particularly those who have severe disabilities, are surrendered to institutions by

parents who are yielding to the recommendations of professionals. Many of these professionals urge parents to go on with their lives and forget about the child, who is depicted as a burden to the family and society. (See Biklen, 1977; Darling & Darling, 1982.)

Responding to the question of whether Jenny's life is worth living, McAlister states that Jenny's spirit is not limited by the confines of her body. "That," he says, "raises the standard of her worth to a higher level" (p.74). In addition to the article about Jenny, there are other indications that imply the solution to the Hamilton's difficulties was to have Joy placed in an institution. Similar evidence is located in the book which was given to Diane when Joy was discharged from NICU. In a discussion regarding children who have severe intellectual disability, the author presents the following point of view:

> In many instances, a retarded child benefits from placement in an institution where there is an appropriate training program than he does from remaining in a home where this could not be provided....The most common practice today [1972] is for a family to take the retarded infant home and care for him so long as they can help him make progress. If his care becomes more than a mother or a family can manage, or it seems likely he will gain more from educational opportunities provided by an institution, then such placement is planned. (Apgar & Beck, 1972, p. 342)

Apgar and Beck's work, which was presented from an exclusively medical perspective, was outdated concerning alternatives. Published ten years before Joy was born and two years before federal legislation mandating special

education for children ages 3 to 21, it did not contain sufficient information for parents to make informed decisions. Joy would have been eligible to receive special education and related services in her neighborhood school the following year. Nevertheless, the family needed immediate relief. As Diane puts it, "For us, we had no choice. We had to put Joy at Johnston. She would have died. She quit eating and lost weight. She cried and screamed constantly."

The Hamiltons were seemingly caught in a bind of insufficient professional advice, lack of personal experience, an inadequate intervention program, and a choice between no community services and total institutionalization. After reportedly searching several options for residential placement, Joy's neurologist informed the Hamiltons that his recommendation was to have Joy placed at Johnston Training School, which he believed to be, by far, the most reputable.

On July 13, 1984, Joy was seen at Crippled Children's Clinic seemingly to gather data to support out-of-home placement. The physician documents on her physical examination report, "Parents are considering institutional placement. We need to be sure [to] be in contact with DDS [Department of Developmental Services] personnel appropriate for this." Records from Crippled Children's Clinic do not indicate that institutionalization is

recommended by its staff, nor is there any evidence that they support the decision. Rather, it appears they could have been opposed to the idea. For example, Diane stated that the therapist seemed puzzled by their decision and asked, "How can you do that...put your baby away? Are you sure you want to do that?" Diane reportedly replied, "I just want a normal life." The therapist indicated on the physical examination report that he discussed Joy's future developmental potential and future care responsibilities with the Hamiltons. There is no indication, however, that he supported the decision for institutional placement.

An application to have Joy admitted to Johnston Training School was dated the same day that she was taken to Crippled Children's Clinic. The reason for leaving Louisberg Special Day School reads, "[it] works like public schools during fall and winter." With the application and necessary documents submitted for admission to the institution, there was only one thing left to do; wait....

Impressions

A common denominator in out-of-home placements for children who have disabilities is an inadequate community and family support system. How much parents are able to cope depends on their innate strengths, on the soundness of their marriage, on the support they receive from physicians, relatives, neighbors, schools, and friends, as well as many other factors (Blacher, 1984; MacMillan, 1982;

Eyman, O'Connor, Tarjan, & Justice, 1972; Handleman & Harris, 1986). The underlying reasons for Joy's out-of-home placement are numerous. One factor appears to be stress related to having a new baby in the home, which meant less time to spend with Joy; a situation not only stressful to her parents but also to Joy. Her parents, being preoccupied with Daniel, were not able to listen carefully for Joy's vocal sounds and respond with their voice and interest. Therefore, the frequency of physical contact and numerous gentle vocalizations with Joy were no doubt curtailed with an infant in the home. Whereas Daniel was able to signal need for frequent social contact every few minutes by vocalizing, making eye contact and physical contact, and getting his parents to respond, Joy, who had the same social needs, was less able to signal effectively. Impaired motor development made it difficult for her to lift and turn her head or to reach out to her parents. In addition, being visually impaired, she was unable to make eye contact. Perhaps Joy did the only thing she could--she cried (see, for example, Finnie, 1975).

It is significant, I believe, that Joy's incessant crying and refusal to eat reportedly occurred only at home and not at school. I think it is likewise important that the behaviors surfaced in May. Diane was anxious about the approaching summer months when the temporal regularity of their lives would be disrupted with the closing of

Louisberg. The program offered Diane "some relief during the day", as Evelyn puts it, and without a summer program for Joy, Diane was apprehensive about the months ahead. Because babies are very sensitive to the mood of the mother, it is possible that Joy sensed her mother's anxiety and transmitted it the only way possible--she cried (see, for example, Finnie, 1975).

Another factor that seemingly contributed to Joy's placement in an institution was stress related to medical bills and increased financial burdens. Living in a rural area seemingly also had an effect. Distance from basic and supportive services, including Joy's intervention program, as well as less access to advanced medical assistance proved to be a hindrance. Stress related to having a new baby, medical bill and financial burdens, an inadequate intervention program, as well as the inconvenience of living in a rural area where factors leading to Joy's placement out of home. The most prominent influence, however, appears to have been the professional dominance of the neurologist and the director of the intervention program as well as information given to the parents when Joy was discharged from NICU.

Frequent extended periods of agitation and distress of children who have central nervous system damage is common. Had an adequate community and support service program been in place to assist the Hamiltons through this crisis, it is

possible that institutionalization could have been prevented (see, among others, Dunst, C., Trivette, C., & Deal, A., 1988; Perske, R. & Perske, M., 1981; Singer, G. & Irvin, L., 1988). A case manager working in close collaboration with the Hamiltons to guide them through the complexities of the service system would have been a tremendous resource. Crisis intervention, respite care (both pre-arranged and on an emergency basis), personal assistance services to assist with feeding, dressing, bathing, and taking care of Joy's personal hygiene, counseling services and a support group, cash subsidies, parent education and training and service coordination would seemingly have empowered and enabled the Hamiltons to keep Joy at home (see, among others, Dunst, C., Trivette, C. & Deal, A., 1988; Perske, R. & Perske, M., 1981; Singer, G. & Irvin, L., 1988).

When the concept of a family support system emerged in my conversation with the family, Clara denounced the idea up front stating, "I don't believe that would have been feasible for this family situation. The only choice was to put Joy at Johnston. I believe she would have died had she not been placed there. Diane just could not take care of two babies."

Diane and Robert will never leave Joy. It broke their hearts to place her at Johnston. They did not institutionalize Joy; society did. For too long we have

separated and closed out children who have severe disabilities and their families. The time is ripe, even overdue for a change. For this cannot be right: Her mother was overwhelmed...her father was doing as best he could...her baby brother was growing...Joy was trying to tell us something...and, Joy was the one who was sent away.

CHAPTER V

JOY' S PRESCHOOL PROGRAM:

A HOLISTIC MODEL IN A MECHANISTIC WORLD

One of the most important things that a child can have is a sense of identity and individualization, and [Johnston Special School]...helps establish that identity. All children are special; all children are different.
--Wycliffe Jones, III, M.D.
(see p. 190)

"The Country Club of Institutions"

A few miles south of a large metropolitan area in the South is a prestigious suburb, the site of magnificent homes, an elite recreation and social clubhouse, a stately golf course, and "the country club of institutions" as it is often referred to by its administrators. Johnston Training School blends esthetically well amid the impressive scenery with its immaculate buildings and well manicured, sprawling landscape adorned with religious relics that signify love and tranquility. The area is a sharp contrast to its appearance 25 years ago when Johnston was built. At that time it was a thickly wooded, isolated and remote region. Only recently, with rapid growth and development, has the surrounding area evolved into an impressive, prominent social setting.

One month after the Hamiltons applied to have Joy admitted to Johnston Training School, they received a letter from the facility informing them that she had been

accepted. Enclosed with the letter of acceptance was a two-page description of the institution titled, "A Special Place for Some Special People." The enclosure begins with a description of the area and states, "After years of prayer and diligent searching [the religious order was] blessed with the perfect location to build a residential training facility for the mentally retarded." A closer view, however, reveals this statement to be a half-truth. The Allen family, who donated the land on which the facility is built, has a different version of the origins of the school. Rather than emanating from the religious leaders, the family contends that the idea of the school was initiated by the family's patriarch. Mr. Allen, a wealthy and influential business leader who had a daughter with intellectual impairment, approached the church requesting that "a school for retarded persons" be built and offered financial assistance as well as the land on which to build it. As Joe Allen, the man's son, unraveled the family's interpretation of the origins of the school to me, I pointed out that it contradicted with that which is printed in a history of the school. Nevertheless, Joe refuted the administrators' version, stating most assuredly that the idea of the school flowed from his father. He nodded and with a smile added, "They have good hearts but are known to twist things for their own purpose."

Johnston is a small institution in comparison to most, serving only 167 individuals. Essentially, it has two programs; one serves nearly 137 persons from 15 to 60 years of age, the other serves 30 children from birth to 8 years of age. There are no children living at Johnston between the ages of 9 and 14. According to the description of the institution sent to the Hamiltons, Johnston "enjoys a reputation for excellence that is known nation-wide--which is reflected in the large number of families from other states that have their children placed in the facility." An implicit message is that individuals selected for placement at Johnston are privileged considering the numerous referrals and requests for admission, which must be approved by a team of at least eight professionals. Accordingly, the outstanding reputation it enjoys appears to be directly related to its selective admission requirements. There is an apparent "creaming" effect in the selection process. For example, all persons ages 15 and older must be ambulatory and cannot exhibit serious emotional or behavioral difficulties. This population is generally docile, conforming, polite and physically able-bodied with fairly independent self-help and grooming skills. On the other hand, the very young children at Johnston usually exhibit multiple disabilities ranging from mild to severe. These children typically have seizure disorders and various medical needs. One criterion for

admission, however, is that they must be breathing without the aid of a mechanical device; children on a respirator or life support system are not admitted. These children, who are primarily nonambulatory, nonverbal, and have little or no self-help skills are permitted to remain at the facility until they are 8-years-old or weigh 45 pounds, whichever comes first. It is much easier to satisfy the physical needs of a child who has no muscle control when he or she is young and small. The problems and needs for training become greatly compounded by growth, making it more difficult to lift, position, dress, change diapers, and feed the older child or adult. Therefore, by admitting only very young children who have severe disabilities and are breathing without the aid of a mechanical device, the facility serves the least fragile of those who have severe disabilities and only the very young as a matter of convenience. As the children get older and their care is more physically demanding, the responsibility is shifted to other facilities, usually state operated residential facilities. Although the majority of these children are 2 to 8 years old, the literature describing the institution refers to them as "babies" and their living unit is identified as "the Nursery."

Correspondence sent to the Hamiltons describing the institution contains two lengthy paragraphs that explain the "training" program for the more able-bodied individuals

15 years of age and older, who are referred to as "residents", and mention that community special schools are available for school age "residents." There is an audible silence regarding programs for the significant others; the children who have severe disabilities. There is no mention of a specialized program for these children, nor any reference to the full-time special school provided by the local school system and housed on the campus to serve these children. In fact, the only reference to this population in the two page, single-spaced description of the facility is one sentence: "All babies (age 1-8) are housed seperately [*sic*] in the Nursery, where they receive 24 hour a day nursing care as they are multi-handicapped with medical complications." The tacit though persuasive message is that these children are permanently invalid and helpless individuals who must live in a hospital-like ward where they are expected to spend their lives hovering near death (see Blatt, Biklen, & Bogdan, 1977).

The description of the facility closes with the following paragraphs:

> With all the "business" of running an institution, Johnston Training School has maintained its personal touch that make [*sic*] it one of a kind. Religious influences are very important and children of all religions, races, and creeds are welcome. The [administrators] at Johnston believe that programming based on Christian love and compassion commits all of the staff to providing the quality of care in which goals are accomplished with kindness, love, and respect for the human dignity of each individual resident.

> So, with the grace of God and a dedicated staff, Johnston Training School is able to provide *an environment of cooperation and growth to maximize the potentials of each and every resident* [italics added].

Conversely, as the story of Joy's life unfolds, what is revealed is that the institution, through its beliefs in mechanistic education maintains the status quo, leaving old attitudes, values, assumptions, and ideas about children who have severe disabilities fixed firmly in place.

The Evolution of Johnston Special School

In 1980 parents of school-aged children placed at Johnston approached the administrators of the institution requesting that their children receive special education and related services as guaranteed under EAHCA, which had been in place nearly five years. Although the institution was privately operated by a religious order, the children were considered residents of Baylor District; therefore, the responsibility for overseeing the children's special education program fell upon the Baylor District School Board. Johnston administrators tried for one year to establish a state approved special education program at the institution but were not successful. When notified by the State Department that all government funds would be withdrawn from the facility unless eligible individuals began to receive appropriate special education and related services, the administrators hastily approached the school board requesting that the school system establish a program at Johnston for the children and adolescents. On

September 18, 1981, I was appointed to the position of principal at Johnston Training School by the Baylor District School Board, three years prior to Joy's placement.

I recall my first visit to Johnston. I was impressed with the immaculate buildings and grounds. The young and middle-aged adults living there appeared to be healthy, happy, and loving. They were excited to have visitors to the campus and embraced each one, almost as if they were starved for contact with the outside world.

I had mixed feelings about the Nursery. It was apparent that the children were given nutritious meals and were bathed and properly clothed. It was a sharp contrast to the conditions described in Blatt's (1974) pictorial essay *Christmas in Purgatory*. The values of shelter, food, clothing, and cleanliness, however, appeared to supersede activation. It was apparent that this sterile, hospital-like ward with metal cribs was a place where children who have severe disabilities were placed to passively live out their final days in a solemn, glum atmosphere. Obviously, the children were not there to enjoy life, to be enjoyed, or to live. Most of the children had not left the ward in the months, even years, they had lived there. They were routinely dressed in the mornings, fed, bathed, and once each day placed in wheelchairs and lined up side-by-side along the wide corridor of the ward. Most of their time,

however, was spent in their cribs. Walking up to their cribs and talking to and stroking these children, many who were abandoned by their families, one could sense their longing for human contact.

Paraprofessional Training Units

State guidelines permit Paraprofessional Training Units (PTUs) in lieu of a special class to provide special education and related services to children who have severe disabilities. A PTU consists of one master teacher and one trained paraprofessional for every three children, with no more than four paraprofessionals and 12 preschool children. The concept was appealing to me; A ratio of one adult to every three children, seemingly meant more "hands on" instruction and attention. Establishing the units, however, was comparable to "blazing a trail." These units were not only the first of their kind in our school system but also the first in the area. The early years were difficult, but within three years I was surrounded by a group of the most dedicated, talented individuals with whom I have ever had the privilege of working. As I spent more time with the teachers, therapists, paraprofessionals and children, I began to sense an extraordinary opportunity for me to be both a learner and a contributor to the learning environment. I began to see myself less as an administrator in terms of management and supervision and more as one who was both gaining and contributing to the

learning and excitement of others. I saw the staff become creators of curriculum and innovators of interventions, displaying fine instincts for working with the children and responding to others. Initially the staff and I welcomed the new behavioral techniques and methods that gave direction to our work with the children, enhanced our skills, and extended our knowledge of how to teach children who have severe disabilities. Strategies including task analysis and instructional techniques such as prompting, fading, and forward and backward chaining provided valuable insight into the mapping of functional skill development. We learned how to systematically teach functional skills in minute, sequential steps. We soon discovered, however, that the systematic techniques deeply embedded in the provision of educational services for children who have severe disabilities were not enough. We needed a more fulfilling, creative, imaginative approach--one that challenged and inspired not only the children, but the staff as well. The time was right for a change; for an alternative approach which viewed the child as a whole functioning within the larger context of her or his environment.

By the time Joy was admitted to Johnston the staff had abandoned the behavioristic model of instruction which we tried to implement in earlier years but were not

successful. We had moved toward a more holistic or organismic approach.

Because education for students who have severe disabilities was beginning to be felt in the region, many teachers were not prepared or certified to teach this population. Responding to the staff's request for teacher education, Jo Fleming, assistant professor of special education at an area university, offered courses for certification. Her approach at that time (nearly a decade ago) was unique for the region. With the cooperation of the university, the school system, and the approval of Johnston administrators, Jo taught courses in educating children with severe disabilities in the classrooms at JTS working directly with the teachers and hands-on with the children. The staff was introduced to new and different perspectives including functional skill development and subsequent environments. In addition, we participated in a research project conducted by Jo regarding the effects of more versus less related services. With her guidance we designed our own record forms for data collection (see Appendix D-1). The collaboration was rewarding, and the changes the staff was undergoing were exciting. Looking back, Jo regards the experience of working with the education staff and children at Johnston as "very special...the most memorable and rewarding in my career," as she puts it.

The staff field tested a popular curriculum for infants with disabilities, and the school was selected as a replication site for the state curriculum for "handicapped infants." However, neither of these curricula nor the others to which the staff had access were appropriate for the population of children at Johnston. Therefore, the teachers and therapists adapted and modified goals and objectives from several sources depending on the child's response and where it was guiding the teacher or therapist. Many times they devised original objectives, sometimes individually, but more often as a team. Rather than fit the child to the curriculum, the staff focused on developing a curriculum *with* each child.

Johnston Training School: A Model of Mechanistic Principles and Beliefs

On August 21, 1984, the special education staff received written communication from the social worker at the institution informing us that "Joy Lynn Hamilton, #503" was to be admitted to JTS.

Diane and Robert arrived at Johnston with Joy on September 4 accompanied by their minister, his wife, and their son. Robert's mother recalls the day when Joy's belongings were packed and they left for Johnston. "I just couldn't go. It tore my heart out to see Joy go. I wouldn't have been any comfort to them. That's why my preacher, his wife, and kid took them."

One of the preliminary steps to enrolling Joy was a routine physical examination by the institution's consulting physician at his office in town. The Hamiltons recall the event:

> Diane: I just didn't like him the first time I seen him. He was just so...I don't know. He didn't act like he cared about Joy at all. He was so ugly, you know? He said, "They got all those teachers out there who think they can teach these kids...kids like yours who have half a brain." He said, "How can you teach kids like this?" I didn't like him.
>
> Robert: Yeah, he was pretty negative. Like there's no hope. He said it's all a waste of time and money.

The consulting pediatrician provided services for the children (and the adults as well) since the institution opened its doors years ago. Being from the old school of thought he was not, nor did he care to be enlightened about new social policy or educational rights for the individuals who lived at the facility. Despite a moral responsibility to the children and that progress can be made under the right circumstances, the medical director was diabolically opposed to having a special education program for the children in the Nursery. Accordingly, there were deep philosophical differences between the medical program and the special education program. The medical program, which had been fixed firmly in place for 18 years, focused on keeping the children clean, fed, isolated and quiet. The goals for the "patient" conflicted with the goals for the "student." The new education model focused on action and

movement toward progress with involvement, interaction and exploration at every level.

The physician often complained bitterly to the parents and administrators that the special education staff was bringing "colds and germs" into the Nursery and contaminating the children. When several children were diagnosed as having strep throat, he insisted that the education staff be tested for the bacteria. (An irony to this incident is that all the education staff tested negative for the bacteria, whereas the nurse, the director of the nursery, and some direct care workers were positive). The pediatrician also complained about the staff's "handling" the children and keeping them in class from 8:00 a.m. until 3:00 p.m. It was his opinion that the staff's contact with the children made them sick. The teachers had a different viewpoint. It seemed that the more experiences they provided for the children, the more they worked with them, interacted with them and exercised their limbs, the more alert and active were the children. The more alert and active the children became, the more attention they demanded. For example, after being in class, many of the children began to cry when left in their cribs for hours after school and on weekends. The special education staff was criticized sharply by Johnston administrators for having too much contact with the children, which they perceived as "spoiling the children";

the children were wanting "too much attention and to be held too often."

A most overt expression of a mechanistic view by the consulting pediatrician was voiced in a meeting with the habilitation staff. Surely, as anyone who was in the room will probably never forget his comment, neither will I. We were meeting to develop habilitation and education plans for another child, Carl. Though, he was a ward of the state, at the time of the conference, Carl was being legally adopted by a teacher on our staff. The conference was attended by at least 10 or 12 people, including the caseworker from the Office of Human Development. When the meeting drew to a close and the teacher who was adopting Carl left the room, the pediatrician looked at me and posed a question that left me speechless. "Now, you tell me," he said, "what's the difference between this boy and a dog?" All movement in the room abruptly ceased. There was dead silence. I sat motionless, numbed by his words, thinking "Did he say that?" "This can't be real." One-by-one I scanned the expressions of those at the table hoping for a sign that one of them would respond, be it the social worker, the director of the Nursery, or better yet one of the religious leaders. There was no indication, however, that anyone intended to speak up. There was an occasional clearing of one's throat, a change in posture, or a glance down at the table but no indication that anyone intended to

respond to the doctor's question. I took a deep breath and with all the composure I could muster I replied, "If no one else will respond to your question, Dr. Sims, I would like to." I remarked that although Carl has severe disabilities he is not a lower form of life. He is a full-fledged human being with human rights. One of those rights is the right to an appropriate education. At that point Dr. Sims interrupted me, citing the example of Pavlov's experiment as the only way children like Carl could learn because, as he put it, they have no more capacity to learn than does "a dog or cat." He denounced the need for teachers, paraprofessionals and therapists to work with the children, stating that the direct-care workers and nurses were capable of "training" the children. I responded once again by saying that we were not "training" lower forms of life, we were teaching children to become as independent as they can possibly be. By involving them in meaningful and normalizing activities and encouraging motor involvement, we wanted the children to learn to manipulate their environment and, to the best of their ability, to become active participants.

At the heart of Dr. Sims' comments lies a mechanistic world view of reality that disregards inner goal-directedness and inner mean-making of children who have severe disabilities; a view that stifles their self-actualization and robs them of their humanness. The

question is, "When will medical science 'discover' the truth about these children?" There are ones with us who have the ability to think, to feel, and to experience the world through their senses. Working with these children, special educators feel the powerful presence of an individual that medical science is slow to acknowledge.

Returning to Joy, the day she was admitted to Johnston was also Diane's and Robert's first visit to the institution. They were given a tour of the Nursery, and I recall meeting them in the hall as they walked toward my office. Like most parents leaving their child for the first time, this was a difficult day in their lives. The Hamiltons seemed to be interested in what was going on in the classrooms but were apprehensive and cautious. I recall Diane addressing several questions to Lorraine, Joy's new teacher. Robert was quiet, very quiet. Like many other parents, they fought to hold back the tears.

Joy's Enrollment at Johnston Special School

The special education staff met with the Hamiltons and a Johnston social worker the day after Joy was admitted to develop an interim IEP for her. She was enrolled in a PTU for infants and toddlers under 3 years of age. Interim goals, according to an IEP dated September 14, 1984, were directed at developing head and trunk control and motor skills to explore her environment; developing early maturation and reach and grasp skills; using functional

imitation skills, playing with objects and developing suitable problem solving skills; developing improved oral motor skills; establishing early attachment behaviors, increasing self-awareness, indicating awareness of others, and displaying emotions; and, communicating with others by expanding her use of vocalizations and nonverbal skills. Additionally, Joy was to receive related services including occupational therapy (OT) twice each week, speech therapy 5 times each week, and music therapy on a consultative basis once each semester. Adapted physical education and range of motion exercises in the whirlpool also were to be provided. The habilitation staff had an overriding concern to maintain strict control of all medical aspects of a child's program. Since physical therapy (PT) was considered to be more medically than educationally related, the medical director preferred that the PT be provided by the institution. Therefore, Joy was to receive physical therapy from the Johnston habilitation staff.

Collaboration: Collective Planning, Teaching, and Evaluation

Collaboration was an important aspect of the special education program at Johnston. The aim was to design a truly integrated program for each child. The occupational therapist, the speech therapist and the adaptive physical education teacher designed objectives for individual children that correlated with the classroom teacher's objectives for the children. The occupational therapist

was primarily responsible for fine motor and self-help objectives, the speech therapist was generally responsible for communication objectives, and the adapted physical education teacher typically oversaw gross motor objectives. Likewise, the teacher designed cognitive and social objectives that correlated with motor, self-help and communication objectives. Each therapist was cognizant of what the other was trying to achieve with the child and supported one another's efforts, working closely with the teacher and paraprofessionals daily in the classrooms to provide individualized services to the child. Rather than pulling the child out of the classroom to provide therapy in an isolated room, the therapists came into the classrooms and worked with the child in her or his natural setting, addressing functional skill development and lending support to the teacher, paraprofessionals, and other therapists. Thus, consistency was ensured in each child's program. There was a team approach not only in designing objectives for the child, but also in implementing them and in evaluating the child's progress.

The collaborative efforts and unity of purpose is best expressed in the philosophy of the special school developed by the staff with input from parents:

STATEMENT OF PHILOSOPHY

> Special Education is an extension of the regular education program which provides the exceptional child opportunities to reach his [or her] potential. Our special school with its professional and

paraprofessional staffs tailors each child's educational program to meet his [or her] unique needs.

> We believe that each child is able to grow and develop socially, cognitively, motorically, and emotionally.
>
> We believe in educational opportunity for all children--the right of each child to receive help in learning to the peak of his [or her] ability.
>
> We work together as a team in a transdisciplinary approach, believing that teachers, therapists, paraprofessionals, administrators, parents, the Johnston Training School staff and the community share responsibility for one consistent, total program for each child.
>
> We have a mutual respect for the individual attributes of our students, teachers, therapists, parents, administrators, the Johnston Training School staff and persons in the community.
>
> We respect the rights of each child, regardless of the severity of his [or her] handicapping conditions, and believe that individualized special education programming adds dignity to the life of the child.
>
> We believe that we must keep informed of our goals and objectives and be open to criticism and change.
>
> We believe that the child's health and emotional state must be optimal if maximum growth and development are to occur.
>
> We strive to provide a continuous flow of opportunities for each child to develop his [or her] maximum ability, and emphasize stimulation through a variety of experiences to help each child become the best he [or she] can be. (Johnston Special School Teacher Handbook, Baylor District School Board Program, 1986-87 p.1)

Staffings were another aspect of the special education program at Johnston that punctuated collective planning, program implementation, and evaluation of progress. The special education program for a child who has severe

disabilities has a tendency to become fragmented with the many disciplines involved in the education and care of the child. Consequently, staffings were held once a month for each child with the teacher, the therapists, the paraprofessionals, the nurse and, occasionally, the parents as participants. Staffings were the thread of continuity that kept the staff moving toward progress with each child. Discussions centered around the child's health, indications of choice by the child, her or his likes and dislikes, what seemed to be working, what wasn't working, concerns, adaptations, and modifications. They were brain-storming sessions that proved to be very productive in terms of searching for new possibilities based upon the signals the adults were reading from the children. Staffings were also the means by which the group arrived at a consensus about the uncertainty of a child's response, determining whether it was volitional or nonvolitional. These meetings were recorded on a single page Staffing Report which was completed in handwritten descriptive notes by the teacher, therapists, and paraprofessionals who worked with the child.

A staffing report dated October 2, 1984, less than four weeks after Joy was enrolled at Johnston Special School is evidence that the special education staff recognized and valued Joy's need for inner mean-making and inner goal-directedness. A paraprofessional records her

interpretation of how Joy signals to have an interaction repeated:

> It's easy to find out what she likes doing, but she wants you to be doing it with her. Example: When playing with the busy box, Joy enjoys it, but she hasn't learned to start the music, so she wants you to do it. She shakes the bells.

Another strong component of the Special School program was a focus on parental participation, which is often a missing link in programs for children in institutions. A school newsletter dated September 1984 and disseminated shortly after Joy was enrolled in the program, carried a special theme encouraging parental participation. Parental involvement was a real concern for the staff. A few parents never visited their child. Some parents, who were attentive and involved when their child was initially placed at the institution, seemed to lose interest and had less contact with their child as time passed. There were several parents and other relatives, however, who visited their child regularly. To encourage classroom visitations and school-parent partnerships, families, relatives, and friends who visited the children were routinely recognized in newsletters. Recognition of the children, however, was the primary goal. To that end, Joy's teacher in reporting the class news for September 1984 writes;

> Joy, a new student in our classroom, has a sunny disposition and a love for music. She enjoys keeping busy by listening to the autoharp and learning to play rhythm instruments.

Joy's presence is also acknowledged by the speech therapist who announces "Joy, who is one of our newcomers, has gone to the 'head of the class' in babbling."

Joy's IHP: A Break in Continuity

Recall that the special education staff observed and informally assessed Joy the day she was admitted to Johnston, then developed an interim IEP the following day. Six weeks later, after weeks of observation and psychological testing, the institution's habilitation staff met with the Hamiltons and the special education staff to develop an Individual Habilitation Program (IHP) for Joy. The IHP, in theory, is to be an extension of the education program with corresponding goals and objectives as well as therapeutic intervention after school hours and on weekends. In addition, an IHP report contains a social history, results of psychological testing and IQ scores, information regarding diet, and a description of needs and services. Following the initial IHP conference for Joy, an elaborate report was completed with more than three pages of activities for Joy after school, including tactile stimulation, positioning and handling, mealtime skills, and motor development. Less than one month later, however, an addendum to the report dated November 27, 1984, specifies that all the objectives for the year developed at the conference were to be discontinued with the exception of two; one that required Joy to respond in a calm relaxed

vocal, facial, or motor response to firm pressure; and, another directed at changing Joy's positions (sidelying in bed, on her front in her bed, and rocking). The addendum specified that in four months the habilitation staff would position Joy "on a slick surface" and over a wedge. Reasons stated for amending the IHP were twofold:

a. The objectives selected are based on the priority needs of the child at this time.
b. ...the staff needs to be trained and closely supervised as the program is developed. As staff are trained and the child is ready, other objectives will be added.

Four salient points regarding the revisons in Joy's IHP are; (a) the revisions reportedly were made without the consent or knowledge of the Hamiltons. They were notified after-the-fact. Therefore, who determined that these objectives were first priority needs? (b) the passivity of Joy's IHP contrasts sharply with the activation required in her IEP; (c) It is highly questionable that a priority need for Joy was to have her develop a normalized touch response (i.e., respond calmly to firm pressure). There was no apparent evidence to support this need. To accept food and eating utensils near the mouth, some children with cerebral palsy need to be touched and massaged around the mouth and lips. Although Joy reportedly was not eating well before she was admitted to Johnston, the special education staff did not encounter significant difficulties feeding her; (d) contrary to the commitment to add other objectives as needed, no objectives were added as the year

progressed. An irony to this discovery is that the Hamiltons placed Joy at Johnston to receive the training and services they could not provide for her at home. Her habilitation program for the year, according to her amended IHP, consisted of no more than having Joy respond calmly to touch (a behavior she exhibited when she was enrolled), changing her position in bed, and rocking her. Even the least trained parent with the least of resources could seemingly provide for Joy what was costing taxpayers nearly $20,000 a year. More important was the cost for Joy; it was at the expense of her freedom and living her life with her family.

Johnston Special School's December newsletter lists Joy as one of several children who went home for Thanksgiving and indicates that she is now saying "mu-mu" for music. Her name also appears with that of six other children who are spending time on the scooter board, and her parents are listed among the recent visitors to the classrooms.

Combined with many documents belonging to the Hamiltons are several copies of the institution's newsletter from the parents' group. Close examination of all issues reveals an audible silence regarding the children who have severe disabilities; children in the Nursery are not mentioned in any of the newsletters. The December 1984 issue (vol. 1, no. 3), contains a typical

format. The newsletter opens with a Christmas prayer from Johnston's administrators, who refer to the individuals living at Johnston as "the little ones." Other than recognition of the founder's 90th birthday, news is primarily of a materialistic nature. (For example, annual benefit drive, completion of a multi-million dollar training center for administrators who manage the institution, and the purchase of two new buses.) A full page message from the social workers announces planned social service activities that include increased parent contact and community awareness to inform "residents" how to deal with situations outside the facility. Dormant near the end of the newsletter is information from four instructors who work with the older individuals at Johnston. Various activities are mentioned, but no individuals living at Johnston are recognized by name.

Media Coverage of Joy's Placement

Ironically, nearly one year after headlines in her hometown newspaper announced that Joy was named the 1984 poster child for the March of Dimes, she is featured once again in an 8-column news article that tells the story of her placement at Johnston. The headline spanning the top of page 5 of the January 2, 1985, edition of The Franklin Observer reads, "Christmas joy shared when family is reunited." The story of Joy's placement opens with the leading sentence:

> A Franklin family received a little bit of "Joy" during the holidays as they were united with their 2 1/2 year-old daughter, who has spent the last four months in a special school near Evansville. (p. 5)

The journalist, quoting from a brochure produced by Johnston, portrays an image of the institution which implies that, considering its strict admission procedures, the Hamiltons are fortunate to have their daughter placed at Johnston. The hype regarding its selective admissions and staff of professionals obscures the fact that Johnston is an institution. Essentially, it is referred to as "a school." The news story points out that although Joy was receiving a day program in a neighboring community, her neurologist recommended Johnston after failing to find a suitable school in the state where the Hamiltons live. Leaving Joy at Johnston was, as related by the Hamiltons, a difficult decision exacerbated by a requirement that prohibited Joy from returning home for a visit for at least six weeks after she was admitted. Close scrutiny of the last paragraphs of the article that explain Joy's daily program reveals that the services described as well as the progress she has made actually represent her special education program. The article fails, however, to make this distinction. The touching story of Joy being reunited with her family at Christmas features a captivating photograph of Joy holding a doll, sitting in her travel chair next to a brightly decorated Christmas tree.

Process and Change in Joy's Second Year of Life

By mid-term her first year at Johnston Special School, according to special education progress reports, Joy had achieved several objectives. She was able to imitate movements such as strumming an autoharp and actions in rhymes and songs such as "Pat-a-cake" and "Row, Row, Row Your Boat." Joy was showing awareness of unfamiliar settings including other classrooms and buildings as well as outdoor areas and the inside of a car, and she was "exploring" them with the assistance of an adult. Progress in communication was evidenced by the vocalizations she was repeating (MaMa, DaDa, Babe). Improvements were seen in motor development as well. Joy's head control was improving and her right hand, which is more involved than the left, was becoming more relaxed with splinting, massage, and tactile stimulation. She was reaching for toys with her left arm fully extended. Areas, however, in which Joy did not appear to be making progress included learning to munch bites of food and making crawling movements on a mat or scooter board.

A multidisciplinary evaluation requested at Joy's interim IEP conference was completed and a report was received in January. Accordingly, another IEP Conference was held on January 21, 1985 to review the report and update Joy's IEP. A specialized staff at the university medical school in Evansville routinely completed

evaluations of children under the age of three for the Baylor District School Board. A critical component of Joy's evaluation process was an examination by a neurologist at the medical center. When examining Joy, the physician detected what was perceived to be seizures and ordered an EEG. Seizure activity was confirmed, and the neurologist recommended that Joy's medication be adjusted. The disclosure that called attention to the need for monitoring of blood levels and adjustment of medication, not only in Joy's case but in other children as well, set off a defiant response by the consulting pediatrician. He demanded, regardless of the children's right to multidisciplinary evaluations, that examinations by physicians outside the facility were not to be performed without his consent.

The evaluation, which was completed before she turned 3-years-old, supported the progress that Joy was making according to her special education progress reports. Two examiners distinctly report that they observed Joy reach for and pat toys, a behavior that will be discussed later in more detail. The report also confirmed the need for the related services as listed on Joy's interm IEP. The IEP committee determined, however, that occupational therapy would be increased from one session per week to two, and adapted physical education was adjusted from small group to individualized instruction, primarily to concentrate on

crawling and other gross motor movements. Two significant modifications to Joy's IEP were recorded: Joy's program was to be in excess of 180 days, meaning that she would have a summer school, or Extended School Year (ESY), program. Additionally, Joy was to receive socialization experiences with nondisabled children. The conference yielded long term IEP goals that were similar to those determined in September and correlated directly to the recommendations in Joy's evaluation report.

Staffing reports continue to reflect that Joy's IEP objectives are frequently adapted and modified. The occupational therapist notes in a February staffing report that she is continuing to encourage Joy to use her right arm, which is more physically involved than her left. The OT further explains that although Joy's right arm is easily relaxed by tapping it above the elbow, Joy will not initiate extending it on her own. The March staffing report reveals that Diane and Robert were participants. Joy has achieved two objectives since the late January IEP meeting and continues to make progress toward the accomplishment of her objectives in all areas. Diane requests that Joy be held and sung to as she eats. The OT records that Diane has suggested some of Joy's favorite foods that the therapist will use to encourage side-to-side motion of Joy's tongue as she eats.

Changes in Johnston Training School

Meanwhile, the private, closed world of Johnston Training School was undergoing rapid change as the institution shifted to Title XIX as its primary funding source. The administrators were pressed to upgrade medical supervision, recreation, training of employees, and move toward community-based programs for many of the individuals living at Johnston. Title XIX regulations required that additional personnel be hired to provide professional and nonprofessional services to the individuals living at Johnston, and provided the funds for salaries, services, and specialized equipment. Several months before the decision to convert to Title XIX funding was made, the chief administrator solicited my input, wanting to know how I felt about the option. Knowing how sensitive the administrators were to maintaining control of operations and their opposition to governmental influence, I assured the administrator that, as I interpreted Title XIX regulations, they were in no danger of losing control of the operations of the institution provided the regulations were met. I considered the move toward Title XIX funding a positive change. It meant opening the doors of the institution and more opportunities for the individuals who lived there. Funds would be available to hire additional professionals to provide services including medical, psychological, social, habilitation and training programs.

I supported the change, excited about the possibilities Title XIX funding held for extending the goals of the special education program after school hours and on weekends. Therefore, I encouraged the administrator to at least try the arrangement. I reminded her that if the program did not succeed or meet her expectations, the institution perhaps could revert to its present program of funding.

The administrator confided that she feared government inspectors would swarm the grounds and invade their privacy. She envisaged a federal inspector appearing unannounced and upon finding their refrigerators and pantries locked, would order the padlocks removed and foods replaced by others not of their choosing. She expressed a concern that the religious symbols and relics also would be ordered removed. There was fear that the administrators would no longer be allowed to control the enrollment and, like huge state-operated institutions, Johnston would lose its "family atomsphere." With my limited knowledge of Title XIX regulations I did not, however, perceive changes of the nature she expressed as occuring.

Conflicts Emerge Between the Mechanistic and Holistic Practices

Eventually, the administrators applied for Title XIX funding and within months monies began to flow through the institution, and the staff grew by leaps and bounds. But, as the Title XIX program expanded, an unexpected turn was

taking place. The new Title XIX staff, confused by its role in providing habilitation services to the children in the Nursery, denounced the "need" for a "school" for the children based on an assumption that direct-care trainers and nurses were capable of providing all that was needed for them. Their beliefs echoed that of the consulting pediatrician. What was initially perceived to be a wonderful opportunity for growth and progress was, in the end, a concentrated effort to eliminate appropriate special education and related services despite the children's legal right to an education.

During the course of the year, a worsening conflict developed between the Title XIX and special education programs with most of the tension evolving from issues related to the medical aspects of the programs and the "need for" special education for "medically fragile" children as well as those under three years of age. A covert movement to close the children's special school was disclosed when parents received a letter dated March 7, 1985, from the administrator of Johnston Training School informing them that due to problems with space, a special school would no longer be on site at Johnston. The letter implied that children determined to be "medically at risk" by the Title XIX staff would receive habilitation services only. The other children would be bused off campus. The parents were further advised that children less than three

years old were "not legally bound by law to receive a formal education" and, therefore, could remain in the Nursery and not be required to participate in an intervention program. Neither the director of special education nor I were aware of the letter until I was contacted by the parents. The Hamiltons were one of many parents who contacted the school, alarmed and confused by the letter they received. Consequently, at the suggestion of another parent, the parents organized and called for a meeting with district school officials, the administrators of Johnston, and the special school staff at the district special education center. The meeting room was packed. Parents had driven from all corners of the state to be there. Some, including the Hamiltons, drove from neighboring states. The administrators from Johnston, however, refused to attend the meeting. Without their cooperation, efforts to resolve the conflicts were at an impasse. Tensions and problems escalated with parents being drawn into the conflicts. Parents reported that when they voiced their concerns regarding the proposed closing of the on-campus special school to Johnston administrators they were told, "If you don't like it, you can take your child out [of Johnston]."

By the end of the school year, Joy had shown progress in many areas. Some of her achievements, according to documentation of her IEP short-term objectives, included

the following: In the area of cognitive growth and development, Joy's imitation skills were continuing to improve. With some assistance, she was imitating simple actions like peek-a-boo by pulling a cloth from her face. She was also learning to give a different response to different objects. For example, she could push a toy, hug a plush animal, tap a rhythm band instrument, and shake a bell or a rattle; in the fine motor area, improvement was seen in Joy's ability to reach with her left arm. In addition, splinting and massaging had decreased some of the tightness in her right hand, and she was relaxing her right arm more often; in the area of socialization, Joy was signaling that she wanted interaction continued when left alone by an adult, and she was acting to have simple action games such as pat-a-cake and peek-a-boo continued. In the area of communication, Joy was learning to repeat vocalizations and body movements imitated by an adult. In an earlier staffing report the speech therapist noted, "She has been inconsistent in responding, sometimes very quiet and [at] others babbling quite a lot. She definitely understands 'imitating' games."

Movement Toward [W]holeness

Although it may appear that Joy's progress, as documented in her IEP, occurred in separate, distinct areas (cognitive, motor, social, self-help, and communication), that was not the case. The changes any child undergoes

involves behaviors that are embedded in all of the areas. Although each therapist and the teacher represented a particular interest area, their responsibility was to the whole child. Albeit the written IEP addresses areas of development separately, the special education staff considered it ludicrous to attempt to teach them as isolated entities.

To illustrate how a totally integrated transdiciplinary approach was carried out in Johnston School, I use an example of one of Joy's cognitive objectives; to encourage her to show a different response to four different objects. In this instance, the teacher works with Joy to teach her to activate, nudge, or propel a push toy. The teacher, however, cognizant of Joy's other objectives and her signals for inner goal-directedness incorporates the following dimensions simultaneously as she works with Joy: A fine motor objective, as determined by the occupational therapist (OT), addresses the need for Joy to use her more involved right arm; a gross motor objective is directed at improving Joy's head control; a communication objective is aimed at motivating Joy to vocalize a consonant-vowel sound; a social objective is focused on having Joy signal that she wants to have an interaction continued. As there are several pieces of adaptive equipment that are designed to maintain head control in midline, the teacher offers Joy a choice; "Do

you want to sit, Joy?" and lowers her near the corner chair, "Or, do you want to stand?" and raises her near a stander. Movements, such as leg kicking or head turning, or vocalizations are interpreted as Joy's indication of choice. Even if Joy is not signaling a preference, the teacher, relying on her intuitive wisdom, imagines what Joy might want to tell her if she could talk and proceeds by telling Joy that she will help her decide. Rather than following a precise schedule for positioning, the reflexive teacher recalls that Joy just came inside from outdoors where she was riding the adapted tricycle; therefore, perhaps Joy would prefer to stand. The teacher places Joy in a prone stander and attaches a tray to facilitate proper head and trunk posturing. Choice is offered not only in positioning, but also in the selection of toys. Joy is given a choice of push toys; the duck or the train. Assisting Joy to feel the toys, the teacher uses her judgment in determining Joy's preference. Joy appears to be more interested in the duck, laughing in response to the quacking sound it makes as it is pushed. Knowing that Joy should be encouraged to use her right arm, the teacher taps it above the elbow to relax the arm, then assists Joy in reaching out with her right hand to nudge the toy into motion. Concurrently, the teacher motivates Joy to vocalize while playing, emphasizing particularly the consonant-vowel sound, "du", in "duck". The teacher waits

patiently to allow Joy to signal by gesture, movement, or vocalization that she wants to continue playing. Or, the teacher may move away from Joy momentarily and leave her alone with the toy to see if she will indicate that she would like to have the teacher return. Thus by addressing the gross and fine motor, communication, and social objectives concurrently with the cognitive objective, the teacher utilizes an approach that is consistent with the overall development of the whole child.

Carrying out one integrated whole program for each child required intensive planning and collaboration. The staff utilized time daily when the children napped following lunch for staffings and to plan and integrate their expertise and skill. All were making a concentrated effort to properly position, lift, and carry the child as well as to promote optimal eating patterns: mouth closure, side-to-side tongue movements, biting, munching, and chewing, as well as the child's use of adapted eating utensils. Conversely, the efforts of the Title XIX habilitation staff, those persons responsible for Joy's program after school hours and on weekends were not as integrated. Inconsistency was due in part to a lack of adequate training but was primarily the result of a strong resistance to change. The direct-care workers were often overheard discussing the changes the institution was undergoing. The expressed opinion of one trainer, who had

been at Johnston since it opened nearly 20 years ago, typically represented the attitudes of most of the workers; "I've been here lots longer than any of them, and if they think they can come in here and tell me how to feed these kids, bathe 'em or put 'em to bed, they better think again!"

Johnston Special Education Staff: Innovators of Curriculum

As the Title XIX staff moved forward to provide instruction in proper positioning, handling, and mealtime procedures to its direct care staff, the special education staff recognized a corresponding need to facilitate a whole program for each child. Conscientious of integrating their services into one whole program for each child, they recognized a need to work with the parents and the habilitation staff who also were responsible for the growth and care of the child. A teacher once remarked in a staffing that it might be helpful to have a picture posted by each child's crib to demonstrate the various positions for reclining that prevent physical deformities and contractures. This suggestion provided the impetus for a brain-storming session from which evolved the concept of a Total Program Photo Essay for the children. To encourage and promote consistency critical to each child's program, still photographs were to be used to show the important aspects of a child's whole program to all persons involved in the care and education of the child. Another equally

important goal of the Photo Essay was to improve parental participation and provide support for parents.

The concept of a Total Program Photo Essay was thus developed and implemented to encourage a holistic approach in educating and caring for the child. We recognized because of the constant changes occuring in a child, there could never be a "Total" program. There was, nonetheless, merit in attempting to combine the different aspects of a child's programs. For lack of a better term we chose the word *Total*. In retrospect, perhaps a better title would have been "Whole Program Photo Essay," as the focus was on the whole child. By telling a story of the day in the life of a child who has severe disabilities through photographs taken from the time she or he wakes in the morning until she or he is put to bed at night, the staff hoped to motivate the consistency in handling and positioning that is critical to the child's health, growth, and well-being. An emphasis was also placed on featuring activities that challenged and enabled the child to participate in and thus change her or his environment. Another significant aspect of the Photo Essay was to stress the importance of having the child participate in environments outside the institution, including home and community. Dr. Jo Fleming, an assistant professor of special education, provided consultation and worked closely with the staff in extending the concept across the child's subsequent environments.

To illustrate effective handling, lifting, positioning and carrying techniques, each child was photographed in the course of her or his daily routines: dressing, eating, toilet use, dental hygiene, bathing, exercising, social interaction, engagement in learning activities, and sleeping. General information specific to the child such as food preferences, favorite activities, and behavior was also included. Captions which included brief directions and any precautions as well as comments were written for each photograph. Careful consideration was given to writing the captions in lay terms, free of professional jargon, so that anyone who read them could understand the directions. The photographs and captions were mounted in vinyl binders with water resistant pages. Each page had 5 sections with slots that allowed easy removal and replacement of photographs and captions. The intent was to continuously update the Photo Essay as the child grew and changed. Book rings were used to attach the photo essays to the child's travel chair to make them accessible throughout the day as the child went about her or his daily life experiences.

Diane and Robert maintained interest and excitement in Joy's special education program but had difficulty explaining her classroom activities to family and friends who wanted to know more about Joy's school. Diane was so eager to share the information in Joy's Photo Essay that

she took the incomplete essay home with handwritten captions to share with family and friends.

The adapted physical education teacher, who was instrumental in planning and organizing individual photo essays suggested that the Total Program Photo Essay concept be submitted in "a competition to challenge teacher creativity" announced by the National Education Association Association and the National Foundation for the Improvement of Education in the spring of 1985. The Photo Essay concept was entered in the competition complete with the endorsement of many professionals who were familiar with the program and had previewed some of the essays. Included from the field of special education was a letter from the Director of Special Education for Baylor District Schools:

> I am so proud that you have expressed in the pictures of these beautiful children, the quality educational services you are providing at Johnston Special School. It is encouraging to me to see the care given to each individual child. The attention you devote to the small steps children must take in learning new tasks is depicted very well. You are also to be commended for the team approach in providing services. I personally believe that, as special educators, you are the best coordinators for the array of services offered and are in the best position to facilitate parental involvement.
>
> The state of the art of educating severely handicapped children may be inconsistent elsewhere, but it is on solid ground at Johnston Special School. Your "hearts" and your "heads" are in the right place and this shines through in your photo essays. The students and parents are indeed fortunate to have access to your knowledge and dedication.

Each endorsement was as unique as the individual who submitted it. The Director of the University Medical

Center's program to evaluate children who have disabilities was empressed with the concept's "potential for extensive replication." On the other hand, an occupational therapist from the center chose to emphasize the Photo Essay concept as an effective means of communication and sharing information. The Executive Board of the regional Association for Persons with Severe Handicaps (TASH) also gave the concept a stamp of approval with the following commendation:

> The Photo Essay submitted by the Johnston Special Education staff is a beautiful illustration of their commitment to meet the total needs of the children served in the Infant Intervention/Pre-School Program. Consistency and continuity in the implementation of each childs [*sic*] Individual Education Plan are key ingredients in facilitating the acquisition of new skills promoting independence in all life areas.
>
> This method is obviously meeting with great success as evidenced in the photos of each of the children included.

Endorsements came in from higher education with associate professors from a neighboring university supporting the concept. (It should be noted that these endorsements were from a University other than the one with which Dr. Fleming was associated.) The Chair of Special Education, emphasizing the wholeness of the approach, writes:

> An added advantage in the Photo Essay is that all of the people who work with the children, those from a diverse representation of disciplines, would be able to see the entire treatment picture, and would be

> better able to see what each discipline contributes to the total special educational program of each child.

A "personnel coordinator for programs in severely and profoundly handicapped" at the same university was impressed with the advantages of the Photo Essay in terms of cumulative record development over more traditional written records. He comments:

> This approach to record-keeping might also enhance the future training of teachers for severely handicapped students, perhaps serving as a preliminary introduction to actual "hands-on" training. In addition, this approach might also be modified to yield equivalent advantages to other areas of special education.

A parent of a child who was not in our program commended the approach stating:

> I am the parent of a severely multi-handicapped child. I was so intrigued with the concept of the "Photo Essay" that I have decided to compile one for my child. I firmly believe that this could be an essential aid in enlightening teachers, para-professionals, therapists, sitters, doctors and other professionals as well as parents in handling, caring and educating the severely handicapped child.

A regular classroom teacher also endorsed the Photo Essay Concept commenting:

> This pictorial record would be of tremendous value to me as a classroom teacher. The background information provided would be very helpful in integrating this child into a classroom setting. This is a much more personal concept than written records.

From the medical profession came the endorsements of a nurse, a physical therapist, and a pediatrician. The physician eloquently focused on the individuality of the Photo Essay approach:

> One of the most important things that a child can have is a sense of identity and individualization and your photo-essay, by individualizing treatment, helps establish that identity. All children are special; all children are different; and what is good for one child is not necessarily the ideal way of approaching another child's problem.

The Professor of Pediatrics and Chief of the Birth defects Center at the local Medical School occasionally visited the program and presented inservice to the staff. The educator and physician writes:

> It is my real pleasure to endorse the Total Program Photo Essay for severely handicapped children submitted by the Baylor District School Board, Special Education Staff at Johnston Training School. Johnston is a well-known residential facility....I have had numerous opportunities to see their patients and share their work. It is a true pleasure to be able to work with such dedicated teachers and workers.
>
> I am very much interested in their photo-essay...for children with severe handicaps. The best part of recording...events of the daily activities involving these children are not well described in the resource books or by the ordinary professional teaching media. With beautifully illustrated photos and clear explanation of the photos, this program will certainly help the education of the parents and the people who work with these children.
>
> I believe the photo-essay method is an exciting idea and program for any person involved in the care and education of children with severe handicaps.

As the endorsements came in, sometimes two and three at a time, the staff often remarked how thankful they were that others had taken time to review the Photo Essays and

make comments. It was reassuring to know the there were persons in the community who supported and valued their work with the children. Each of the endorsements was special. There was one, however, that stood out from all the rest. Because it so eloquently represented the staff's goals, the endorsement of the Associate Professor of Pediatrics at the local medical school is presented in its entirety:

> It was a pleasure meeting with the personnel at Johnston Special School last Friday and to view first hand the program depicted in your Photo Essay for Severely Handicapped Children. The photo essay album itself is pleasing to review, easily understood and practically self-explanatory without having the 'slick' look of a piece of professional propaganda. It tracks closely with the objectives stated. Those objectives themselves are concise, clear, and admirably free of jargon.
>
> After visiting your physical plant and examining most of the children in the most severely affected section, one is impressed with how well you practice what you preach. Most commendable of all to me (because it is so rare among institutions) is your stated objective and working practice of making your clients and their families less, rather than more, dependent on the services which you provide. The album especially facilitates this objective.
>
> Thank you again for the opportunity of visiting your operation. I am pleased to endorse it, both in concept and in execution.
>
> With continuing best wishes to you, your staff and your little [students], I am...
>
> Sincerely yours,
> Frederick B. Bolton, M.D.
> Associate Professor of Pediatrics

The Total Program Photo Essay concept was submitted to the national review panel designated to judge the entries

(see page 190). Mailed with a written report of the project were samples of individual Photo Essays and the numerous endorsements. There was, however, what the staff perceived to be a serious omission; the endorsements of the administrators of Johnston and the attending pediatrician, which, next to that of the parents, would have meant the most. The administrators and the consulting physician were given copies of Photo Essays to review, but chose not to endorse the concept.

"We Want Joy Lynn to Get What She is Getting Now"

Problems between the Title XIX and special education staff escalated. "Finally," as a parent (of young adult living at Johnston) who served as a mediator to resolve the conflicts put it in a written report, "the Baylor District School Board was given the ultimatum by Johnston to remove all equipment from the campus or be evicted by the sheriff." When attempts to resolve the conflicts collapsed, all equipment and supplies belonging to the special school were removed from the campus at the close of the summer program and stored at other schools in the district.

A note from Robert Hamilton dated July 8, 1985, to the director of special education typically represented the concerns of the parents relative to the removal of the special education program:

> Please make a note that we do not want any change in Joy Lynn's special education program. We do not want

> her to be bused off of campus either. We want Joy Lynn to get what she is getting now on campus (Johnston Training School) and not an itinerant teacher program.

The reactions of the parents stemmed from the letter they received in March from Johnston administrators informing them that the special education programs of children who remained on campus would be reduced to part-time hospital/homebound instruction.

Meanwhile, joint meetings with the relevant regulatory agencies (Title XIX and Special Education) at the state level to resolve the conflicts proved productive, and on August 19, 1985, a headline appeared on page 8A of the Baylor Times which reads, "Baylor teachers back on Johnston Training School campus." The article opens with rhetoric about problems with space, then quotes a teacher who gives an accounting of the parents' delimma. She is quoted as saying, "[The parents] have seen their children make progress in this program. The homebound service--three hours of instruction per week as opposed to 5 1/2 hours, five days a week in the on-campus program--was never intended for the severely disabled." The article, which covers half the page, concludes with a statement from the Director of Special Education: "We are proud of our staff. I think I can truthfully say that the Baylor District on-campus program at Johnston Training School is recognized as a model program in [this state]."

Negotiations at the state level reportedly made it clear that educational decisions, including those regarding placement, were to be made at IEP conferences with input from parents. Essentially, Johnston Administrators were told that parents and educators make decisions regarding the children's special education programs, not the Title XIX staff. The Title XIX staff was not pleased with the directives. The special education program was allowed to return to the campus, but was moved to the opposite end of the nursery in the infirmary. The Title XIX Director of Habilitation informed the education staff that a line was drawn at the nurses' station, and they were not permitted to go beyond that point. The special education staff was not allowed to go into the area where the children's cribs were, nor were they permitted access to the children's medical files. Any medical information needed would have to be requested in writing. In addition, the education staff could no longer use the dining area for the children; the children were to eat lunch in the classrooms.

In the midst of the struggle, the staff received news that gave them hope. On September 3, 1985, another headline appeared in the local newspaper, "Rewarding work--Special ed program gets national recognition." The article announced that the staff "accepted a 'challenge to teacher creativity' and emerged winners." The journalist reported that from a field of 1,000 entries, the Photo Essays were

chosen one of the top seven winners. Quoting from a letter announcing the results of the competition, the reporter writes:

> The judges called the reports fantastic...a superb example of the kind of creative program development that teachers can accomplish when given the necessary support. We laud your unique contribution to the improvement of instruction...

According to the list of winners, the Photo Essay project was the only one from the field of special education. Other winners represented various fields of general education including social studies, math, biology, and the arts and humanities.

Fear of Change: A Mechanistic Model Forces Control

Major philosophical and programmatic differences between the Title XIX habilitation program and the special education program resulted in divergent goals; whereas, the special education program was promoting the concept of one coherent, integrated program for the whole child, Johnston administrators and Title XIX personnel insisted on complete separation of the two programs. As the arbitrator put it in a written report, the education program favored joint resolution of all issues with substantial meshing of programs. The Title XIX habilitation staff demanded complete separation of programs to such an extent that the special school was moved to the most remote and isolated area of the campus; the infirmary at the opposite end of the Nursery. The special education staff was forced to

work with little contact with the habilitation staff, including the nurse.

Beyond the rhetoric of problems with space and territoriality lay the real reason for rejection of the special school; fear of change. An assistant superintendent from the Baylor District School System perhaps came very close to the real issue when he visited the program and offered his opinion regarding the conflicts. Dr. Blanchard believed that the issue of space was used to mask an intense effort to do away with the special education program because it reflected the inherent inadequacies in the Title XIX program. With the special education program as a model in place, the Title XIX program was constantly striving to live up to the higher expectations of parents and the community to serve the children who were proving that, given the right conditions they could make progress. As deficiencies in the medical and habilitation programs surfaced, the more resistant the staff was to change. The quickest and easiest solution was to force closure of the special school.

The special education staff perceived the conflicts to be related primarily to the medical staff's overriding concern to control all aspects of the children's lives. The special education staff was perceived as stepping over its boundaries in medical concerns. However, as the arbitrator's report points out, the consulting physician

"is not accepting of education's responsibility as it interfaces or overlaps with medical matters. His personal style and his influence upon [JTS administrators] and parents is a factor in continuing problems.... The physician's attitude is mirrored when the medical staff interacts with the education staff." An example of this behavior is succinctly illustrated in an exchange dated May 26, 1986, between a teacher and a nurse as documented in a log book. (Rather than allowing conversation and information to flow freely and naturally between the education and nursing staffs, it was controlled by means of the log.) Note especially the nurse's deliberate response to the teacher's question.

> Teacher: I remember in staffing that Shamekia is on 75 mg. of Dilantin, but how many times a day? S.C.
>
> Nurse: Why? J.M.
>
> Teacher: I would like to know because I am concerned about her. If the dosage is low for a child her size then the problem of hyperplasia is not an immediate concern. If it is a moderate or high amount then we will begin gum massage. I think you know what a difficult job that will be on Shamekia. I didn't think it would be wrong to ask since it was mentioned in staffing. I just wasn't tuned in when [another nurse] mentioned the frequency of the dosage. S.C.

Mechanistic Practices and Holistic Principles: Divergent Planning, Evaluation, and Programs

Although the Title XIX and special education staffs were meeting jointly with the parents to develop habilitation (IHP) and education (IEP) plans, collaboration and coordination between the two programs was almost non-

existent. Consider, for example, the objectives developed for Joy at a joint IEP/IHP conference on October 7, 1985. IEP fine motor objectives were directed at having Joy develop grasp and release and to activate toys and various switches. The IHP objective, however, required that Joy, in supported sitting, reach out and touch a toy placed near her, a skill which Joy had been demonstrating for nearly ten months, according to her IEP dated January 18, 1985. Evidence supporting the IEP is the evaluation report completed by the specialized team at the medical school; two examiners state that they observed Joy reach out and pat toys during the testing situation. Similarly, a subsequent multidisciplinary report dated March 5, 1985, lists one of Joy's strengths as her ability to "reach for the source of noise." Although there were some objectives for health care, the one and only habilitation objective for Joy remained the same without modification for 10 months, from October 1985 to August 1986. Also unsettling is the criterion to determine mastery of the skill; Joy was required to reach out and touch a toy near her "once each session for 23 sessions each month for 3 consecutive months." Whereas Joy was placed in various positions (sidelying, sitting, sidesitting, and standing) during school hours to activate toys, her IHP reveals that after school hours and on weekends, she was placed only in supported sitting to reach for toys.

Other evidence of control by the medical staff was found in the attending pediatrician's resistance to outside medical evaluations and services that did not originate with him. Joy was continuing to be followed by her pediatrician in Monticello, and it was he who recommended in the summer of 1985 that her adenoids be removed and tubes placed in her ears due to recurring ear infections. Records reveal that shortly after the medical staff received the recommendation, Dr. Sims sent Joy to be checked by two other physicians (apparently at one visit in October 1985) who "did not recommend surgery at the present time." The difficulty with Dr. Sims' sending Joy to be examined by the two physicians is that whereas Joy's pediatrician had followed her since birth, the other physicians seemingly saw her only once. There is also evidence that they did not have access to all of her medical records, an issue that is addressed later in more detail. More importantly, neither Robert nor Diane recall being contacted regarding the examinations.

Holistic Inclusion: Community Participation and Interaction with Typical Peers

One aspect of Joy's special education program as documented in her IEP was socialization with nondisabled peers. As the children were institutionalized, education's goal for integration was twofold; the staff wanted to open the school and invite the community into the classrooms in addition to taking the children out into the community.

Accordingly, the staff planned frequent field trips to broaden the life experiences of the children with activities in environments outside the institution. These were not recurring daily or weekly excursions for systematic instruction in community settings as proposed by Snell (1983). They were, nonetheless, meaningful experiences for the staff and the children as they learned a new interrelatedness outside the classroom setting. Favorite outings included a Safari petting zoo; a riverboat ride; a picnic and outdoor games and activities (organized by the adapted physical education teacher) at a community park accessible for children who have physical disabilities; the Rose Center and Gardens; a local museum; the mall at Christmas to ride Santa's train and have his picture taken with the children; the State Fair; the community arts and crafts extravaganza; the Botanical Gardens; and live children's productions such as *Sesame Street Live!* Parents were invited and encouraged to join the children on these outings. Diane, Robert and Daniel often accompanied Joy on field trips when Robert had a day off at the firestation. A letter in Joy's school file dated October 8, 1985, from Diane expresses her appreciation for being invited and taking part in a recent field trip.

To encourage interaction with nondisabled peers arrangements were made with friends, relatives, and

neighbors to have their children accompany the children from Johnston on field trips. Other activities included bringing neighborhood preschool children to the classrooms on Fridays to play and learn with the students. On a few occasions a child was taken to a day care center in the community where the teacher remained with the child to encourage meaningful experiences for all.

Joy's Special School Measures Up: Holistic Education Generates Success

December 1985 marked a significant moment in the history of Johnston Special School when the state Office of Special Education conducted a routine triennial on-site monitoring of the Baylor District school system. The compliance chief from the Office of Special Education visited Johnston Special School to evaluate conformity with state and federal mandates. The monitor visited the classrooms and interviewed the teachers, then randomly selected the evaluations and IEPs of three students to review. One of the three requested was Joy's IEP. The monitor scrutinized the IEPs and asked questions pertaining to flexibility of the curriculum, collaboration in planning and evaluation of student progress, least restrictive environment, and parental involvement. She carefully checked each section of IEP, paused for a moment, then remarked, "If I could have just one wish, it would be to take thousands of copies of these IEPs, go up in an airplane and drop them all over this state for everyone to

see how they should be done. These are excellent." In an exit interview with Baylor central office staff, the monitoring chief reportedly told Baylor administrators that in the many years she had worked for the state, she had visited virtually all the programs for "the severe and profoundly handicapped," and Johnston Special School was the best by far.

A brief one-page summary of the Monitoring Report dated December 12, 1985, recognizes only one of the 76 Baylor District Schools; "Johnston Special school was commended for its excellent program and IEPs." IEPs elsewhere apparently were not meeting standards as the district was cited for deficiencies in at least two areas: "1. Current Performance-more descriptive information was needed. 2. Some goals had no criteria for evaluation." In contrast to the assessment of the Johnston staff, the summary further reveals:

> There was an overall concern among the monitors that teachers felt IEPs were little more than a piece of paper--not a coordinated plan for the student.... More in-service on the IEP was recommended.

The summary also recommends that the Baylor District School Board "get help from the State Department in resolving problems at Johnston." Although the State Department offered to conduct an internal investigation to help resolve the conflicts, the superintendent reportedly declined the offer.

Mechanistic Model Forces Reduction in Services

Although the December monitoring report was a source of inspiration for the education staff at Johnston, the year did not end on a positive note. Not only was the special school more isolated than before, but the staff was experiencing pressure from the Title XIX staff as it maneuvered to control and reduce special education services to the children. One example lies in a directive from the physical therapist informing the special education staff they were no longer permitted to give the children water exercises in the whirlpool. Although water exercises supervised by the therapist had been a part of the children's IEPs for 4 years, he ordered they be discontinued. With the stroke of a pen, the whirlpool exercises were suddenly redefined as therapeutic treatment to be administered only by the physical therapist. When questioned about the order, the therapist stated that he was fearful of losing his license because the exercises were being performed by persons other than a therapist. The therapist, who worked on a contracted basis part-time for the institution, shared the same beliefs as the Title XIX staff. He was opposed to a special education program for the children in the Nursery. When he began working at Johnston three years before, he boastfully announced that he complained to his school board member about the money being spent to provide the special education program at

Johnston, which he considered a waste. He likewise was opposed to the abundance of adaptive equipment and materials the school was accumulating. His position seemed paradoxical. On the one hand, he was a professional dedicated to physical treatment of the body to relieve pain, prevent disability, or restore function; on the other hand, he was vehemently opposed to the purchase of adaptive equipment for children for proper body alignment, for correct posturing, and to prevent deformities.

The value of whirlpool exercise for a child who has cerebral palsy is binary; the whirlpool soothes the body, relaxing the tightness in the limbs, which are more easily stretched in the water, and it is also an enjoyable, soothing, experience for social interaction as the child splashes, claps and kicks. The benefits afforded the children were worth the time invested in soliciting donations for the whirlpool, ordering it, and having it installed in the Nursery (with the consent of the Johnston Administrators). Likewise, it seemed worth the effort to obtain an interpretation of the provision of the service at another level. Therefore, a member of the Board of Medical Examiners was contacted for another opinion regarding the risks to the therapist when the education staff exercised the children in the whirlpool. In a letter dated December 10, 1985, the Board member attached a copy of the Physical Therapy Practice Act (as amended 1983) with appropriate

sections marked and explained that whirlpool exercises could be performed by the education staff and advised that the treatment be referred to as relaxation and not physical therapy. Referring to another large school system in the state, the therapist pointed out that children in that district are given exercises "designed by a therapist but carried out by a non-therapist teacher or aide." He further stated that the treatments could be under the guidance of the nurse, not necessarily the therapist, and "should be indicated as such to cover all bases." The examiner also imparted that the therapist should not be concerned about losing his license provided he implements treatment based on prescription or referral of a licensed physician.

Despite the written assurances from a member of the State Board of Medical Examiners, the education staff was not permitted to continue exercising the children in the whirlpool. The Hamiltons, like many parents, protested. Nevertheless, Joy, who was exercised three times a week in the whirlpool as documented in her IEP, was no longer to receive the treatment.

Holistic Education: Positive Growth and Change in Joy's Third Year of Life

Change, modification and adaptation typically describe Joy's education program as evidenced in her IEP and monthly staffing reports. For example, by mid-term her progress report (January 10, 1986) indicated that after hearing

songs or performing actions Joy imitates them later in the day. Her teacher noted that Joy will "stamp" her feet when she hears "stamp, stamp, stamp your feet" in an action song played frequently in the classroom. Joy also fills in "ee-i-ee-i-oh" for Old McDonald after hearing it played or sung and is thus also learning to take turns. The game they play is a familiar one: The teacher sings, "Old McDonald had a farm ..." and Joy sings, "ee-i-ee-i-oh."

Joy is also learning to use objects like a hairbrush and a toothbrush, although she needs help to hold them. One of her objectives, to drop small toys and blocks into a pail or other container, is entertaining to Joy. A paraprofessional notes that Joy's improvement is not measured so much in actually dropping the toy into a container as it is "in the enjoyment she gets with the paraprofessional's help."

The education staff noticed that extended breaks in school (holidays, summer vacation, or absences due to lengthy illness) often resulted in children returning to class exhibiting self-stimulatory behaviors. Aversive treatment was not the approach used to address these responses, which often subsided when the child was returned to the classroom and engaged in meaningful activities. Such was the case with Joy who was apparently demonstrating some self-stimulatory behavior when school resumed following the Christmas break. A comment in the staffing

report of January 10 reads, "Joy is no longer sucking her hand or throwing her head back as much as she used to." She had learned to inhibit these behaviors when told "no," but the staff was working on consistency.

Joy is also learning to balance herself momentarily in sitting without assistance. The adapted physical education teacher notes; "I usually use a [cassette] tape of her family talking to her or a story telling tape. This usually keeps her attention..." Another change in Joy is that she has learned to vocalize to have a toy returned to her that was taken away. This change in Joy required reciprocal changes in the therapist's approach, for as she noted in a staffing report three months before, "Joy did well with this objective for awhile but has not been consistent lately. We will continue to look for toys which she is really interested in."

An important aspect of Joy's program focused on learning cause and effect and making choices. Joy's personal autonomy was enhanced by the use of microswitches which enabled her to play with battery operated toys of her choice and to start and stop her tape player. She was learning to use a variety of switches, including a plate switch, a pressure switch, and a pull switch that each produced a different auditory effect. The speech therapist notes that Joy has learned to imitate pitch changes during nursery rhymes and games. Improvements in receptive

language, in comprehension, and in social development are evidenced by Joy's kicking her feet or giving her hand to the teacher when asked.

The occupational therapist states that Joy is learning to bear weight on her elbows and to hold a toy with her right hand which has more tonicity than the left. Difficulty is noted, however, in learning to eat finger foods. Joy is unable to dip her finger into the peanut butter without full assistance. She can, with a little less help, turn her wrist so she can get her finger into her mouth. A month later (February 3, 1986) the therapist has modified the self-feeding objective to have Joy reach for the peanut butter on a plate.

Teachers and paraprofessionals, rather than the nurse, frequently were the first to detect a child's illness, sometimes days or weeks in advance of an official diagnosis. Acute attention to shifts in a child's mood and signals of irritability or discomfort were clues that alerted the education staff to a child's impending illness. Such is the case when Joy's teacher noticed a change in her as documented in the medical log on February 13, 1986:

> Joy hasn't been eating very much this week--drinking some today, especially. Seemed not to feel well. Took to nurse...took temp., 102° 2:50 p.m. L.W.

Joy was apparently experiencing the onset of an illness that was to last 2 to 3 weeks. A staffing report dated March 5, 1986, reveals that some of the gains Joy

made up to early February have slipped. The occupational therapist writes, "Joy has been absent several days this month, and several days in class it seems that she was not feeling like herself." Similarly, her teacher and paraprofessionals note that Joy is not showing progress on seven of ten objectives. Her speech therapist echoes this concern; "Joy was attempting to imitate some sounds before she got sick a few days ago. She is just now starting to do this again." Documentation of this nature is important evidence of regression required to support a recommendation for an Extended School Year Program (ESY). Joy's illness was confirmed in a Title XIX IHP review for the month of March which states that she was treated for an ear infection. (Recall that Joy's private pediatrician recommended surgery to address this problem over 6 months ago; the consulting pediatrician at Johnston, however, had her evaluated by two physicians who did not support the recommendation.) By March the adapted physical education teacher has learned that she needs to modify an objective aimed at teaching Joy to imitate crawling movements. After trying several weeks on a mat with little success because of Joy's difficulty with balance, the teacher is placing Joy on her stomach over a bolster or a roll to steady her as the teacher and a paraprofessional move Joy's arms and legs through crawling motions toward a desired toy or an

individual. Using the bolster, however, does not appear to help. The teacher describes the problem:

> Joy Lyn *sic* needs full assistance with her arm movements and she has changed her hip and leg movements to bouncing action instead of crawling action. I will continue with this objective and try other ways to encourage crawling movements.

Movement, excitement, and variety typically represent the day in Joy's classroom. Considering that preschoolers are active and curious, the children's positions were rotated at least once every 15 minutes or sooner, depending on the signals they transmitted for change. Staffing reports reveal that Joy experienced a variety of positions daily: She is placed on her stomach and bears weight on her elbows; she sits in a corner chair or stands in a stander while playing with toys or operating a switch; she is placed over a large vestibular ball and rocked to relax the tightness in her body; and, to help her learn to reach for toys when she is in her crib, she is placed sidelying with her head on a pillow and her hips bent. The side she is placed on is changed alternately so that she reaches for the toy with her left hand at times and with her right hand at others. In addition, videotapes and photographs of Joy reveal that her classroom is often moved outdoors where she is learning to move forward in a walker, to ride a bicycle (sitting supported in a carrier behind the adapted physical education teacher), to propel an adapted tricycle forward

with the assistance of an adult, and to swing in an adapted swing pushed by an adult.

Teacher Creativity, Intuition, and Autonomy

Spring marked the district's annual field day event. In keeping with the district-wide celebration, the adapted physical education teacher ensured that the children at Johnston were not excluded from the celebration. Creativity in individually organizing the day's activities for each child led to the success of field day. Each child participated and each one was a winner. Events included scooter board races, crawling contests, rolling contests, head-raising contests, sitting contests, walker races, tricycles races, and batting at an overhead ball suspended from the ceiling. Paraprofessionals, therapists and teachers encouraged and cheered the students to push the farthest distance, to be the first to raise their heads using a mercury switch for motivation, and to sit unsupported the longest before losing balance. In a videotape of the event, Joy is plastered with blue ribbons. She, like all the others, won a place in each event in which she participated.

By the end of the school year the speech therapist notes that Joy has achieved a communication objective aimed at having her imitate new sounds. The therapist explains that although Joy does not try to imitate all new sounds, "*she does try to do the ones she is interested in*, and even

though she does not always imitate exactly, it is obvious she is trying" [italics added]. Accordingly, the therapist has acknowledged and demonstrated respect for Joy's impulse for inner goal-directedness in learning to communicate with others.

Teacher autonomy and judgment are revealed in a comment by the teacher regarding a social objective which has been modified due to Joy's visual impairment. Joy is to indicate that the cause of an action is outside herself by touching an adult or a toy after the adult has activated a musical or noisemaking toy. The teacher writes, "She has met the criterion for the objective--but social interaction is very helpful to Joy, so we will work with this objective longer."

In regard to Joy's learning to use objects like a toothbrush and a hairbrush, the paraprofessional observes that Joy seems to enjoy using the hairbrush; however, "she wants to move her head rather than the brush..."

A favorite toy for many preschoolers is a large ball, and Joy is no exception. Her teacher states that Joy is enjoying playing "ball" with the other children. The teacher has adapted the game by sitting Joy on the mat "Indian style" with Joy's back against the teacher's chest. The teacher helps Joy extend her fingers over the curvature of the ball and push it toward a child and a

paraprofessional facing them in the same position on the opposite side of the mat.

The OT has mounted a large peg on a tray to enable Joy to steady herself as she reaches to grasp toys and objects on the tray. Joy is learning to hold onto the peg with her right hand, which helps to keep her arm extended, as she reaches for items with her left hand. The therapist observes that Joy is more able to keep her right arm outstretched on a toy or peg when her left hand is also outstretched to the toy.

Joy can rattle toys and with help is learning to combine toys in motor play by banging them together, dropping them in a container, and stacking them. She is learning to reach above, up, to the right and to the left to retrieve toys. As the school year ends what may appear to be insignificant changes or only slight improvement is progress that keeps hope alive for more growth.

Johnston Special School Collapses

Immediately prior to the opening of the school year the education staff at Johnston received official notice that the special school was to be dismantled due to budget cuts and a projected decline in enrollment. The ultimate irony was that as the special school for children with severe disabilities was being dismantled because of budget cuts, the program for children who are gifted was expanding with the hiring of additional teachers--(Baylor District

School Board Budget Application, 1986-87). In addition, although there was a projected decline in enrollment, the Nursery has been operating near or at capacity enrollment since the fall of 1987. Whose values did this decision reflect? Foster (1986) challenges researchers to study the field of administration by its reconstruction as a moral science and as a critical science. Pointing to the moral and political implications of administrative decisions, Foster reminds us:

> Facts are identified as facts only through our values; in making any kind of decision, the administrator is advancing someone's values. Every decision about what "is" the case is also a statement about what "ought" to be the case. A decision to close a school, for example, may be an expression of the hard-headed fact that the school system needs to save resources, but it is also a statement of values and of priorities: *this* school ought to be closed because no other option is viable. (p. 64)

Although dismantling the school meant a reduction in staff and transferring the school principal and the secretary, two PTUs remained on site at Johnston. The therapists and adapted physical education teacher, who were no longer assigned full-time to the program, provided only itinerant services. Joy's teacher, Lorraine, who remained at Johnston describes the effects of and adjustments to the change:

> We try to keep it altogether, but it seems to be falling apart. No one at the special ed. center seems to really care about the children or our program. They rarely come out here... only for an IEP conference, or to have us fill out forms. And, when one of them walks in, regardless of how busy we are with the children, we are expected to stop what we are

> doing and complete a report or fill out an order. I remember how important instructional time used to be. Like it was almost sacred, you know? Not anymore! It's like the reports and forms are more important than the work with the children. We just didn't realize how much paper work [the school secretary] did for us. It's so frustrating to have our time with the children interrupted, and no one seems to really care.

Process and Change in Joy's Fourth Year Life

A joint IHP and IEP conference was held on August 27, 1986. Joy's habilitation objective remained essentially the same as it had for two years but with a slight yet significant modification; Joy will no longer be allowed to listen to her musical tapes for relaxation and pleasure, during meals, after school hours, or on weekends. Listening to music is restricted as "Joy will be rewarded with 60 *seconds* of music *only* when she is in the day room and has responded to reaching out and touching an auditory cued toy for 23 sessions a month for 3 consecutive months" [italics added]. The Hamiltons protested, and Joy's teacher expressed her concerns as well. As Diane put it:

> I told them they better give her tapes and tape player back to her. Her music is the only thing she really likes. It's like her security blanket, and they were tryin' to rip it away from her. Sometimes when you talk to them, they just look at you like you're crazy. Like you don't know what you're talking about.

Robert echoed Diane's point of view:

> I don't know where they come up with some of their ideas, but it seems that they don't really think about Joy...how she must feel; like she's being punished. And, when you tell them something, they act like they don't hear you. It's cruel to take her music away like that.

Lorraine, Joy's teacher, also expressed concern about the habilitation objective:

> I understood how they were going to use her music as a reinforcer, but I couldn't believe that they were going to take it away from her like that! Diane and Robert spoke up at the meeting, but you know what good that does.

A glaring inconsistency in Joy's IHP evolves around the issue of the habilitation objective that remains essentially unchanged for two years. The objective, as mentioned above, requires that Joy reach out and touch a toy near her "once each session for 23 sessions each month for 3 consecutive months." The Title XIX occupational therapist stated in the same IHP report, however, that she observed Joy to be able to purposefully reach for objects.

Evidence of a declining special education program and diminishing services are revealed in Joy's IEP. Physical therapy, which has been provided by the habilitation program, is no longer listed as a related service. In addition, the frequency and amount of speech therapy is reduced from 5 times per week to 2 times per week. This adjustment is apparently made not in regard to what is best for Joy, but in the interest of accommodating the program changes; it is more convenient for an itinerant therapist to provide therapy twice a week rather than once a day. Other significant omissions on the IEP are whirlpool (relaxation) exercises and socialization with typical preschool children.

Corresponding to diminishing services is an apparent disintegration of the education team. Collaborative planning, teaching, and evaluation decline as IEP participants are unable to attend monthly staffings due in part to itinerant scheduling. The single-page monthly staffing report with comments and recommendations from each staff member responsible for the child' s program eventually gives way to separate progress reports submitted by each provider.

Records reveal that Joy continues to have recurring ear infections (6 within 12 months) and in late October the Hamiltons take her to a hospital in Monticello where "buttons" are inserted in her ears and her adenoids are surgically removed. In October the physical therapist, who ordered whirlpool exercises discontinued for nearly a year, has decided to resume the exercises; however, direct-care trainers, not the education staff, are to provide the service.

Evidence that choice and personal autonomy is continuing to be addressed in Joy' s education experiences can be found in the December staffing report. Joy is asked if she wants to listen to a favorite tape, to be pushed in the swing, or to hold her toy vacuum cleaner.

Joy completely recovers from surgery and by mid term is demonstrating steady progress in many areas. She is able to hold a toy in both hands, indicates a desire for

adult help with a toy, and imitates the sounds of a duck, a sheep, a dog, and a cat. She sporadically also imitiates laughter and clapping. In regard to Joy's progress in imitating animal sounds, the speech therapist remarks, "I am glad Joy loves this objective so much, and I feel she will continue to make progress." Joy's balance in unsupported sitting is improving slightly and she is continuing to keep her right arm outstretched momentarily when her hand is on a toy or a switch. She is also reaching for a toy when side-lying propped on one elbow, and is learning to hold to a cup while taking a sip of liquid.

Joy's family not only maintains regular contact with the school and the facility but consistently includes Joy in holiday and family celebrations and remembers her on special days and events. An example is found in the letter she received from her mother for Valentine's Day 1987:

> Joy Baby,
>
> Mommy and Daddy just wanted you to know we Love you! Daniel sings songs to you and stands in the chair and looks at your picture. Each morning he tell[s] me he wants to see Joy. I promise that we are all coming...next week, so be sure to tell Ms. Judy [paraprofessional] and the other[s] to be awaiting for the Hamilton Family.
>
> We are sending you a Family tape and a new tape and a big amount of Love. The [chocolate] heart is all your[s]. Tell those teachers its o.k. to make a [mess] this time...Tell [the trainers] to take good care and to give you lots of kisses from Mom, Dad, [and] of course Daniel.
>
> We Love You,
> Mommy
> Daddy
> Daniel

Modifications and changes continue to be documented in Joy's program as the teacher adapts the objective for Joy to hold a toy with both hands to having her "do something" (activate a toy) with each hand. In addition, the OT notes that she has been encouraging Joy to "search" for a toy out of reach. When sidelying and propped on her right elbow, Joy has been reaching for a toy or switch several times each session.

Exchange of information between the habilitation and education staffs appears to have been interrupted with the dismantling of the special school. Without the assistance of a school secretary or access to a copy machine, teachers were apparently unable to forward monthly staffing reports to the habilitation director. Joy's April habilitation report discloses that the February staffing report has not been received from the education staff. It further reveals that education progress reports will be forwarded to the habilitation staff each nine weeks rather than once a month.

By the end of the school year, staffing reports indicate that Joy's imitation, play, and problem solving skills are improving. She repeats movement with a suction toy, her "Joy" doll, a musical turn toy, and a toy piano to continue the toy's actions. She has also learned to remove a cloth from her head (by moving her head or sweeping the cloth with her hand) when asked "Where's Joy?", and to say

"boo" when her face is uncovered. Her exploratory reaching is improving when she is sidelying and a toy or switch is moved several inches to either side of the original location. The OT reports, "Joy occasionally adjusts her arm and hand toward the moved toy and touches it, but her performance is inconsistent." In the area of communication Joy has been making vocal approximations and gestures for "yes," "no," "up," and "bye-bye." According to the speech therapist, "Joy is doing great and we are very encouraged by her progress!" Bearing weight on her knees and hands with her arms fairly straight has proven to be very difficult for Joy. Her adapted physical education teacher notes that the objective has been discontinued and a new objective designed, changing her position to prone with her arms outstretched and elbows slightly bent.

As the school year ends, communication difficulties between the special education center and the staff remaining at Johnston causes apparent confusion regarding summer school. Neither the parents nor the teachers were informed about definite plans until "the last minute." Lorraine recalls that unlike other summer programs which had plans in place for weeks, the education staff at Johnston was not informed about the plans for their program until the Friday before classes started on Monday. A document belonging to the Hamiltons seemingly supports her assertion. The Supervisor of Special Education in a

written response to a letter of inquiry from the Hamiltons regarding Joy's summer program verifies the dates for summer school (ESY) to be June 3-30. Noteworthy, however, was the date of the supervisor's letter; June 5, 1987, two days after summer school began.

The summer staffing report reveals that Joy "had a very good summer school." Emphasis was placed on Joy's vocalizations, having her to use her hands to operate toys and switches, and increasing her social interactions. She also reportedly enjoyed using the walker and listening to and participating in a good morning game each day.

Process and Change in Joy's Fifth Year of Life

In a surprising move, the habilitation staff schedules Joy's annual IHP conference on August 6, 1987, weeks before the education staff is to report to school, thus marking the beginning of separate IEP/IHP conferences. Interestingly, however, many of the objectives and activities previously mentioned in Joy's IEP are beginning to surface in her IHP: the use of a peg on a lap tray to extend Joy's right arm for short periods of time, having Joy adjust her reach as toys are moved to different locations in front of her, encouraging Joy to hold her cup when she drinks, having Joy maintain a sitting position, and use of a walker. The IHP reveals that the Title XIX psychologist observed Joy spontaneously reach and hit objects, push objects of which she was tactically aware,

hold objects placed in her hands, and bang objects to make sounds. Similarly, the Title XIX occupational therapist's report discloses that Joy is beginning to adjust her reach to either side and upward as a toy is moved to different directions. These observations precisely support the gains documented in Joy's IEP.

There is a notable difference in the IHP social service summary, which for three years contained a statement regarding the Hamilton's hopes for Joy's future; "Mr. and Mrs. Hamilton continue to have hopes that Joy will one day be able to return home with them when more appropriate services are available in their area for meeting her special needs." This statement is omitted from the 1987 and subsequent IHPs.

Although the education staff was not represented at the IHP conference, records reveal that a social worker and a nurse from the habilitation staff are present at an IEP conference on September 21, 1987. The special education center is apparently out of compliance with federal and state mandates that require annual IEP updates by the anniversary date or sooner, if needed. The anniversary date for Joy's annual IEP conference has been missed by nearly a month. Further reduction in related services is evidenced by the frequency and amount of occupational therapy, which has been reduced to one-half of that provided in previous years. There is no indication that

Joy will be receiving water exercises or participating in activities with nondisabled peers, neither is an extended school year program recommended.

Despite efforts by Joy's teacher to continue staffings, it is apparent that without leadership or support of the special education center, the monthly staffings have been discontinued. Progress reports, however, are completed each nine weeks and mailed to the parents.

The first nine weeks' report of progress reveals that Joy continues to make slight, though significant changes. According to the OT:

> Joy has shown a great deal of improvement in the use of her left hand/arm to "search" for a [noisemaking] toy that she likes, especially when the toy is moved side-to-side. She continues to have difficulty, adjusting her arm upward to "search" for a toy.

The adapted physical education teacher notes that with minimal assistance Joy is setting off her tape player by pressing her left hand against a switch while in the prone stander. The speech therapist comments that the paraprofessional greets Joy and says "up" when lifting her out of her wheelchair, out of the corner chair, or off the mat, and Joy is responding to "hi," "bye-bye," and "up." According to the therapist, Joy's "actions indicate a good understanding" of the words. She nods her head "yes" to "Jesus loves me" (a phrase and response that orginated with her parents) and turns her head side-to-side for "no" when

she does not want to eat anymore food. One of the paraprofessionals remarks that Joy is reacting differently to textured objects, and another paraprofessional comments that Joy is listening and responding to a variety of words and requests. Her teacher relates that Joy is given named objects which are then hidden, and she is to find the named objects by means other than vision. Progress is also documented in social interplay and social awareness. For example, a third paraprofessional notes that Joy loves to play "find the toy." Joy is also showing progress in offering her hand or an object following a request such as "give me your hand," or "hold my hand."

A Case of Conflicting Information

It was detected several months before that Joy could possibly have a dislocated hip, and a letter of November 16, 1987, addressed to the Hamiltons from Shriners' Hospital informs them that surgery to correct this problem is scheduled for January 7, 1988. Records reveal, however, that the surgery was rescheduled when on that day the consulting pediatrician for Shriners' raises concern regarding the last phenobarbital level which was taken three months before and was below therapeutic levels. Concern regarding the phenobarbital level is reiterated by the consulting neurologist at Shriners' who advises, "Get the phenobarb level to at least 25 prior to surgery." The neurologist's handwritten report also reveals apparent

difficulties with exchange of medical records from Johnston and perhaps holds the key to understanding the cause of Joy's disabilities:

> hx [history] of birth would be helpful--?small head at birth--this would suggest congenital anomalies of brain as etiology ex [*sic*] head was normal size at birth then a perinatal problem would have to be considered.

My suspicion regarding the events of Joy's birth was aroused once more by the neurologist's comments. Referring back to the medical records of Joy's birth, I learned that her head circumference at birth was 34 cm. Plotting this measure on a head circumference chart reveals that it falls precisely at the average head size for a newborn girl. This discovery did not surprise me as the photographs of Joy in NICU seemingly depict no visable abnormalities. Inexplicable, however, is that which is missing from the head circumference chart plotted by the NICU neurologist. Although Joy's head size is plotted from about the age of three months to 2 years, showing an abnormal rate of growth, her head size at birth is not plotted on the graph. Why would the neurologist who attended Joy when she was in NICU choose not to plot her head circumference at birth on the chart? Joy's average head circumference at birth, according to the comments of the neurologist from Shriners', seemingly indicates that brain damage may have occurred sometime during the birth process, not before her birth as the parents were reportedly told.

When I shared the information from the neurologist's report from Shriners' with the Hamiltons, Robert raised a valid question:

> I've always doubted the story about the knot in her cord. I was sitting right there when Joy was born. If there was a knot, I believe he [the doctor] would've said something. If it was there, why didn't he show it to me? Or, say something to the nurses? Nobody said anything about a knot in her cord. If it was there it seems like he would've cut out that part [of the cord] to show us later, or take a picture of it or something.

Robert's comments triggered Diane's memory of a friend's situation:

> Yeah, like what happened to Sherry. I have a friend and her baby died when it was born. But, they let her hold it. Then they [hospital staff] took pictures of it. They told her they had to. They did it to, you know...to protect themselves.

"Joy Has More Abilities Than May Be Measured by Standardized Assessment Instruments"

Returning to a discussion of Joy's schooling, records reveal that in January 1988 Joy was referred for a routine triennial re-evaluation. The referral source interview indicates that Joy's teacher believes that she would benefit from a less restrictive placement with interaction from peers. In addition, the referral denotes that her teacher is of the opinion that Joy's level of functioning should be upgraded from the profound range to the severe range.

During a 20-minute observation, the psychologist noted that Joy was on-task for 90% of the observation time. "Joy's on-task behavior was characterized by hitting a

switch to activate a toy. Off-task behavior was characterized by random head movements or noises."

Joy's teacher has been using sandpaper letters to introduce the letters in her name. She has Joy feel the letters in her name in hopes that she may one day be able to braille. Another activity involves using large buttons in configurations that represent a J, an O, and a Y. Joy enjoys these activities and has learned to say the name for letters, J and O as she "brailles" the corresponding sandpaper letter or button configuration of the letter. The staff is pleased with these changes in Joy, but her teacher is concerned that the obvious progress Joy has made will not show up in the tests to be administered to her in the evaluation process. She expresses this concern in the teacher interview contained in the evaluation report:

> The teacher remarked that Joy is exhibiting an interest in learning as evidenced by her beginning rote spelling of her name. She is beginning to sing phrases in nursery rhymes and songs on command and spontaneously. Joy is able to respond to simple questions and commands such as "hold my hand" and say "bye-bye." Joy is demonstrating many emerging skills and [her teacher] feels *Joy has more abilities than may be measured by standardized assessment instruments* [italics added].

A diagnostic assessment of developmental functioning supports Joy's progress as documented in her IEP. The report indicates that Joy's scores are considered to be an underestimate of her true abilities because of vision impairment and motor involvement. Despite the teacher's assessment of Joy's ability, the progress Joy has made, and

the acknowledgement that her test scores were lowered due to her vision and motor impairments, Joy continues to be diagnosed as having profoundly impaired intelligence.

The hip surgery, which was postponed in January, is performed in March. A report by the orthopedist reveals that Joy's "surgery was canceled due to a subtheraputic [*sic*] phenobarbital level as well as sinusitis." The physician notes that Joy's phenobarbital level was still "slightly subtheraputic [*sic*] upon admission [this time] and was raised appropriately after talking with...the Neurologist."

Holistic Practices Provide New Possibilities For Learning

The end of the year progress report indicates that one of Joy's favorite activities involves the large alphabet book with the sandpaper letters of her name. Joy reaches and searches for it when the paraprofessional playfully hides it. Joy is even using a pawing motion to turn the pages. She says "book" when she wants to play with it, and says the names for the letters as she purposefully strokes the letters with her hand. Encouraged by Joy's apparent interest in "brailling," Joy's teacher requested the consulting services of a vision specialist employed by the school system. Lorraine was optimistic that the specialist would be able to give her some advice and recommendations to assist Joy in this new avenue of learning for both of them. Lorraine's excitement and eagerness quickly turned

to despair, however, when the specialist visited the classroom. Lorraine describes the experience this way:

> I didn't think she would ever come. It took her so long to finally get here. I had to go through so many channels just to try to get her out here. Then, she walked into the room and took one look at Joy and said she was "too low." She didn't even spend any time with Joy. She just looked at her and made the assumption that Joy can't learn. I just don't understand it! I was so hoping she could give me some real good ideas, but that didn't happen. She didn't stay more than a few minutes, and she was gone. Then, I got this written report from the specialist that said Joy didn't have the cognitive ability to benefit from vision services. She had evaluated Joy in a matter of minutes and that was not even what I wanted. I wanted suggestions.

A similar situation occurred when Lorraine requested that Joy be considered for computer assistance or augmentative communication services. The therapist (who was based at Evansville) reportedly read Joy's records and without observing her declined the request, stating that Joy was "too low" to benefit from services.

Progress is Qualitative Changes Over Time

The Data Record Form (see Appendix (D)) used to document progress toward objectives was designed by the staff to record not only the numerical data (number of trials) but also descriptive data and comments. Consider the qualitative changes recorded by one of the paraprofessionals working with Joy on a social objective that is aimed at having her repeat a social interaction that is fun for her. Reading Judy's comments sparked

memories of her special relationship with Joy and both of them playing and laughing as I had seen them do so often:

> 1/29 Rolled over & over on mat--both of us laughing
> 2/1 Rolled over on mat with her. I took her hand and rolled her on her back again. She thought this was a game and we did it several times....
> 2/5 The game is for her to roll over, to get away, and for me to catch her and roll her back....
> 3/10 Rolled over on mat and I chased her--she laughed
> 3/15 She loves to play the chase game on [the] mat

Joy's teacher notes on the end of the year progress report that even though Joy does not consistently name or give objects upon request, she should be credited for responding appropriately at times. For example, she has frequently answered "Joy" when asked what is her name. When the adults sing the alphabet song and pause after the letter I, Joy says "J". She also says "book" when working with the alphabet book and "ding" and "dong" when playing with the bell.

The adapted physical education teacher observes that, following her hip surgery, Joy is beginning to once again show progress in moving forward on the scooter board with leg movements. The speech therapist relates that Joy is imitating two-syllable words with pitch changes; for example, she vocalizes "bye-bye," "a-boo," "good girl," and "bee-bee" for baby. Other new words in her speaking repertoire include vocalization for "smooth" when feeling objects with slick surfaces and "ush" for push when pushing a toy or object.

The summer program marked the end of the special class setting at Johnston. Lorraine, another teacher, and the paraprofessionals who continued to work there following the dismantling of the special school were transferred to other schools in the district. The children's IEPs, in most cases, were revised to indicate hospital/homebound instruction rather than full day special class placement. An itinerant teacher served the children two afternoons a week. For the children who remained in the Nursery, instructional time was reduced, in most cases, from 330 minutes 5 days a week to 120 minutes 2 days a week. Joy was one of three children bused to Evansville Special School continue receiving education services in a PTU.

An IEP dated July 12, 1988, confirms Joy's placement at Evansville. The Least Restrictive Environment assurance statement reads:

> Joy has made a lot of progress while at Johnston Training School and it is felt that placement from residential to a special school campus would be less restrictive. She will need placement in a PTU to take care of her special needs.

As the story of her experiences at Evansville unfold, the irony to her transfer to the community special school reveals that her placement there was more, rather than less, restrictive.

CHAPTER VI

JOY'S EARLY ELEMENTARY PROGRAM: A MEDICAL MODEL DEEPLY ENTRENCHED IN MECHANISTIC PRACTICE

Evansville was built for orthopedically handicapped children, not the severely retarded...these others just don't belong here.
--Former Principal,
Evansville Special School
(see p. 234)

According to a brief history of Evansville Special School as outlined in its *Handbook for Professional Personnel* (Revised October 1986), origins of the school can be traced to January 1945 when it was organized pursuant to Act 163 of the 1944 state legislature which provided funds for the education of "physically handicapped children." Known as the "Cottage School," it was sponsored by the Baylor District School Board and the Evansville District Children's Association. The school had one class with a teacher and 35 children and was located in the ladies' rest room on the State Fair Grounds. The purpose of the school "was to provide instruction and recreation for children who were unable to attend a regular school" (p. 6). The Baylor Foundation for Exceptional Children and the Baylor District School Board jointly financed a facility consisting of temporary buildings and in 1948 opened Evansville Special School. When additional funds for the education of exceptional children were made available through an act of

the state legislature in 1950, Evansville was "designated for the orthopedically handicapped" (p.6). Four years later, two acres of land owned by the state was donated to the Baylor School Board and construction of a new facility was underway. September 1956 marked the opening of the school at its new site, which is where it is housed today. In September 1967 the school was racially integrated.

The brief history of Evansville seemingly implies that the school provided services to all children with orthopedic impairments in Baylor District. A glance back at Paul's situation (see Chapter I), however, reveals that was not the case. There was an exclusion policy that restricted enrollment to only those students who were "educable" according to an IQ test. Psychological testing to determine eligibility for enrollment at Evansvilles was confirmed by an occupational therapist who has worked there periodically since the mid 1950s.

A View of Evansville Special School

Evansville Special School is located at the rear of a university medical school and adjacent to the Shrine Hospital. Like the institutions that surround it, Evansville Special School depicts a hospital-like setting. Generally, the speech therapist, the OTs, and the PTs wear white lab coats. Likewise, the full-time nurse in white uniform is employed at the school. The atmosphere is usually glum and solemn. Other than the occasonal playing

of a children's record and transfer of children to and from the temporary building for adapted physical education, there is not much sound or activity. The staff generally communicates in soft voices, and on occasions when a child cries out or talks loudly, there is a rush to quieten her or him. The implicit message is that the children who attend Evansville School are ill.

A massive concrete bus dock runs the length of the back of the building where the children, most who are in wheelchairs, are taken out of buses in the morning and returned at the end of the school day. A large concrete ramp extends from the loading dock, allowing convenient access to the building for children in wheelchairs or other mobility devices. The school plant is a striking contrast to other community schools in that playground space is extremely limited. The small areas that are available (one on the north side and another on the south side of the building) are rarely used.

"<u>These Others Just Don't Belong Here</u>"

"Evansville was built for orthopedically handicapped children, not the severely retarded. Our school is for children who are educable; these others just don't belong here," was the resounding message of the principal in the early 1980s when the population of the school was changing. As some parents began taking their children out of institutions and bringing them home to live and to attend

school in the community, many were enrolled at Evansville. Changes occurring in the population of the school were under the protest of the principal. "Institutions are for children like this, not Evansville," she once told me.

At a forum in the early 1980s for parents of children attending the four special schools in Baylor District, parents of children with severe disabilities who were enrolled at Evansville also were objecting loudly. Concerned about inadequacies in their children's programs, they were calling for immediate change. The emotional protest of one parent who addressed the group is vividly recalled:

> They're not doing a thing for my child! For two years everytime I go into his classroom, all I've ever seen is an aide get out of a chair and rush over to him and start ringing a bell in his ear. (Gestures ringing of a bell next to her ear). I'm tired of this! Something needs to be done; not later, but now! My son's life, his time at school is being wasted. We hear this district is doing some good things for the children at Johnston, but what about our children at Evansville? We want the same for them.

The principal for Evansville was not present at the forum. Following the meeting, which went well into the night, the Director of Special Education approached me as I was leaving the building. We walked outside together where she expressed her reaction to the meeting:

> Dorothy (the principal) has some real problems at Evansville. She sees the population of the school changing, and she doesn't like it. But, I've told her she needs to get used to it, because it's the coming thing--the new wave in special education. As more orthopedically handicapped children from her school are placed in regular schools, severely handicapped

> children will be taking their places at Evansville. I see more and more of these children entering our system, and the logical place for them is Evansville. You know, Dorothy really needed to be here tonight to hear what these parents are saying.

At that point the Director solicited my help in assisting the principal at Evansville in reorganizing the "multihandicapped" classes into PTUs.

The principal contacted me within a few days and I met with her at Evansville to share the concept of the PTU as it operated at Johnston. I particularly emphasized teacher autonomy in assigning responsibility for the children's instructional programs in ways that were compatible for both the teacher and her paraprofessionals. The active role of the paraprofessional in planning, instructing, and evaluation was also discussed. The significance of monthly staffings was explained. State guidelines for PTUs were shared with the principal as well as copies of the Data Record Forms, samples of children's schedules, and some curriculum guides the teachers were adapting to use with the children. Following the meeting, the principal gave me a tour of the two classes for "those pitiful children for whom there was little hope." Most of the children in the multihandicapped classes were confined to their wheelchairs all day, and though it was not intended for this purpose, the state's *Separate Minimum Standards for Moderate, Severe, and Profoundly Handicapped* was used as a curriculum for instructional purposes. Adaptive equipment and

materials in the two classes appeared inadequate. Most important, the staff working with the children did not seem to be knowledgeable of advances and new technology in the field.

In one of the classrooms, though most of them were in wheelchairs, there were two children lying on a mat and one reclining on a large bean bag chair. None, however, were properly positioned to prevent deformities. Pointing to the girl resting on the bean bag, the principal stated that a fly could light on her face and she would never know it. "She's one of the lowest we have, and her parents want her in a regular school! That's so unrealistic. There is no way she could benefit from it, and just think of how the other children will act when they see her," commented the principal. (Today as a result of her parents' persistance, this young girl attends her community high school, and her parents recently won a law suit in federal court allowing them the right to videotape her IEP conferences.)

"Discontinuity: We Tried to Tell Them, but They Just Didn't Listen"

Although records reveal that the annual review of Joy's IHP and IEP were held on the same day (July 12, 1988) it appears that separate conferences rather than a joint meeting were held. There are no signatures of the habilitation staff on the IEP and, likewise, no signatures of persons representing education on the IHP. Apparently the IEP conference was primarily for the purpose of placing

Joy at Evansville, as only the placement page of the IEP is completed. Recall that when Joy was to be admitted to Shriners' Hospital for hip surgery her phenobarbital levels were too low according to two physicians. Her IHP Annual Health Care Review seemingly contridicts the physicians' observations. Consider the comments regarding her hip surgery:

> On 11/2/87 she was checked at Shriners' Hospital for hip surgery which was scheduled for 3/28/88. She underwent [the surgery]. She did very well after surgery. Phenobarbital level within therapeutic range.

Contrary to the summary, records reveal that when Joy was seen at Shriners' in November, her surgery was scheduled for January 11, 1988, not March. Recall that when she went to the hospital in January, her surgery was cancelled due to a subtherapeutic level of phenobarbital. The surgery was apparently rescheduled for March 28, at which time her phenobarbital level remained below therapeutic levels. This time, however, the neurologist apparently increased the dosage of the anticonvulsant medication and surgery was performed.

A second IEP conference is held on September 21, to plan Joy' s education for the new school year. The resulting IEP, however, bears little resemblance to Joy' s previous IEP and, thus, marks a significant disruption in the continuity of her growth and development. The Evansville staff determines that Joy will no longer receive

direct occupational therapy, only consultation twice a month. Thirty minutes of physical therapy is to be provided once a week. Speech therapy and adapted physical education, however, remain unchanged. The length of her instructional program is 180 days according to the IEP; therefore, Joy will no longer participate in an Extended School Year Program. The IEP also reveals that Joy will not have any activities or experiences with non-exceptional peers. New IEP goals and objectives are written which have little correlation to Joy's previous IEP. There is a striking contrast between the active IEP developed at Johnston and the primarily passive IEP at Evansville. A significant part of Joy's program, according to the IEP, is aimed at rotating her positions during the day among the corner chair, the side-lyer, her wheelchair, and the mat. Other objectives are aimed at having Joy "tolerate a trainer stroking her face" and "accepting food and liquid from different caretakers." She is also to "allow a spoon to be placed near her mouth and accept food." In contrast to Joy's previous IEPs which had numerous objectives for cognitive growth, there are none to address this aspect of Joy's development. Whereas all areas of Joy's growth and development were addressed in previous IEPs, the focus seems to have shifted primarily to positioning, that is, rotating her positions, and to motor development. (See

Appendix B for a comparison of the two schools' goals and objectives).

The communication objectives come closer than the others to approximating Joy's previous IEP. Joy is to make a choice of two objects, initiate a play activity twice a day, and engage in turn-taking activities twice a day. There are no objectives however, aimed at having Joy make vocalizations and interact verbally with others.

Another striking contrast between the two IEPs is the section that gives general information about Joy. Whereas the previous IEP emphasizes Joy's growth and changes over time, the Evansville IEP describes Joy with pejorative medical jargon that focuses on her limitations. An example of these descriptions is found in Appendix C.

The Hamiltons relate that they were not pleased with the quality of Joy's IEP. Since Evansville, however, was new to them and to Joy, they were hoping that once the staff worked with her, they would recognize that Joy was much more capable than that which was reflected in the IEP. The Hamiltons repeatedly made one request. As Diane puts it, "We kept telling them, 'I wish you would talk to her previous teacher. She's known Joy a long time, and she can tell you a lot about her.'" Robert adds, "We tried to tell them, but they just didn't listen."

Controlling Aspects of a Mechanistic Model

The Hamiltons received a copy of the "Parent's Handbook" for Evansville Special School when Joy was enrolled. The stated purpose of the handbook is "to define the role of the parent, student and staff in the educational process," and new procedures are presented to reverse a trend of declining parent participation. It appears, considering the controlling aspects of the directives to parents presented in the handbook, that it may be defeating its purpose. For example, there is a time limit on conferences not to exceed 25 minutes. In addition, if a conference involves related service personnel (OT, PT, or speech therapist), the conference is scheduled at the child's therapy time. A message from the therapists to the parents also does not appear to be conducive to partnership. Parents are instructed to send wheelchairs, walkers and crutches to the school for school use and reminded that "school equipment may not be borrowed in its place."

Another directive from the therapists seemingly implies a tacit message that parents are not capable of making good judgments related to minor adjustments to adaptive equipment and wheelchairs. For example, the parents are instructed, "Before making any adjustments of equipment (such as position of pads, headrest, straps, etc.) please contact your child's therapist." Parents who

have questions about treatment are instructed to "call and make an appointment for discussion during their child's therapy session." Another directive that implies control is a statement from the speech therapy department to the parents: "You will insure the proper care an operation of...equipment, etc. sent home with your child."

The handbook extends an invitation to parents of children in "the multi-handicapped classes" to eat lunch with their children and states that days will be set aside for this purpose. Consider, however, the contradiction to the invitation revealed in Diane's recounting of a visit to the school:

> Any time we walked in that school it seemed cold. The people weren't very friendly. The first time we went to see Joy after she was placed there, we were standing there in the front [lobby] a long time before anyone said anything to us. Then finally this therapist, or maybe it was a paraprofessional, came over and asked us if we needed something, and we told her we came to see Joy. And, she told us, "Well Joy's eating right now, and you might disturb her, so why don't you wait here." I got so angry. I told her, "I'm Joy's mother, and I don't think I'll upset her. We drove 150 miles to see her, and I want to see her now."

Robert added:

> Yeah, what they were saying didn't make any sense. We just walked on through to the room. I know now why they didn't want us to see it. There were so many kids in there--a room full--and they were crying, and it was so noisy. I don't see how any of the kids could eat.

Meanwhile, events were occurring locally and statewide that eventually would impact on Joy's special education program. A newsletter the Hamiltons received from the Special Education Department reveals that controversy regarding Extended School Year Program (summer school) is escalating statewide. Local parents (some with children who are or were former students at Evansville) join efforts with other parents throughout the state and by mid-term the state is involved in a consent decree regarding Extended School Year Programs for children who have disabilities.

Process and Change in Joy's Sixth Year of Life

Joy's mid-term progress report reveals that her time in the standing table has increased, she is "tolerating" other positions, she is "almost enjoying her lunch hour," she is imitating sounds and is making noises and fusses to get attention. It is noted that Joy will not hold onto an object, nor will she reach out and attempt to grasp one. The speech therapist indicates that "Joy enjoys finishing a song when the therapist stops singing or the tape goes off." According to the PT, positioning and standing continue to be addressed, "range of motion has been unchanged," and gross motor level remains the same." There is no report of progress from the OT.

A follow-up appointment at Shriners' in March reveals a contradiction to the PT report of progress in late January. According to a report sent to Johnston from a

nurse at Shriners', "Dr. Richmond emphasized aggressive PT as very important in her care." It has been only a year since Joy underwent hip surgery, and an X-ray reveals her right hip to once again be at risk. In addition, splints were prescribed to prevent contractures in her hands and ankles.

An IEP conference was held the following month apparently to synchronize the anniversary date of Joy's IEP with the school's procedure to hold annual IEP conferences in April. Despite Dr. Richmond's recommendation for aggressive PT for Joy, her IEP reveals that Joy's therapy was not increased, rather it was decreased from one 30 minute session per week to one 30 minute session per month. Regardless of concerns also about her hands, indirect OT services (consultation only) was reduced from 2 times per month to one time per month. Speech therapy remained unchanged. Although a consent decree regarding extended school year programs was in force, Joy's IEP indicated that she would not have a summer program, nor will she participate in activities with nondisabled peers. Joy's IEP for the coming year remained much the same with emphasis primarily on rotating and tolerating positions. Three additional objectives required that Joy "cooperate and participate in a body awareness program" and use her right hand to touch a toy. Social objectives required that she "cooperate with the trainer in playing simple games"

and decrease self-stimulatory behaviors. Joy was also to drink from a cup held by a trainer and accept more textured food. (The IEP indicates that Joy is given pureed food, which is another evidence of inconsistency or regression; previous IEPs, multidisciplinary reports and IHPs reveal that Joy had been eating ground food since she was 2 1/2 years old). Joy's communication objectives appeared to be repetitions of skills she acquired also at two years of age: to press a switch plate to activate a toy, to press a switch plate to activate a tape player, and to make a choice between two toys activated by plate switches. In addition she was to wave bye-bye or verbalize "bye." Other than vocalizing "bye" there were no plans to concentrate on Joy's vocal communication with others. Joy was also to "tolerate [a] trainer stroking her face" and not resist tactile activities including textures and temperatures. Joy's adaptive physical education objectives remained the same. She was to turn her head toward the direction of a sound and reach toward the object, (a skill she was demonstrating also at two years), and weight-bear, and hold her head erect and her back straight in supported sitting. Her speech therapy, OT, and PT objectives were duplications of her previous IEP goals and objectives.

Records reveal that an IHP conference was held on the same day as the IEP conference. It appears, however, that these were separate conferences with no representation of

the education staff at the IHP conference, nor representation of the habilitation staff at the IEP conference.

A statement in the IHP summary indicates that "Johnston and Evansville staffs held Joy's program development jointly." A review of the special education center's computerized data file of IEP participants reveals, however, that there were no representatives from the Johnston Staff at the IEP conference on April 14, 1987, and supports the committee signatures on the IEP.

The IHP physical therapy evaluation consists of two brief sentences: "Joy is about the same and has made very little progress in the past year. She does continue to have problems when working in a quadrupeds [*sic*] position over a bolster." There is no reference to the splints or the orthopedist's recommendation for aggressive PT.

Mechanistic Practices Catch Up With Joy

Joy was seven years old when the 1989-90 school year began and assigned to Maria Lopez's PTU. The first nine weeks' progress report revealed that Joy mastered two objectives: tolerating the standing table for 30-45 minutes, and tolerating being positioned in the corner chair, her wheelchair, the floor sitter, and the mat. Ms. Lopez indicated, however, that these objectives were to be on-going. Joy was eating well, and the texture of her food

was to be gradually increased. According to the adapted physical education teacher, Joy mastered the objective to turn her head to the sound of a noise-making object and search for it, but the speech therapist revealed that Joy has shown little desire for a choice of objects. The PT noted that Joy was "standing well" in the stander and had lost some shoulder motion. There was no indication, however, that therapy was to be increased nor any reference to splints or the concerns of the orthopedist regarding her right hip that was at risk.

Evidence of separateness and lack of coordination between Joy's habilitation and education programs is found not only in the absence of an aggressive PT program as recommended by the orthopedist at Shriners' but also in references to the texture of her food. At the institution Joy's food was ground and at school it was pureed. In addition, there is no evidence to indicate that Joy was wearing her splints to school.

Mid-term 1990 marked the beginning of my field experiences at Evansville. I was pleased to learn that Joy's teacher was Maria Lopez. Maria is a conscientious and caring individual whom I have had the privilege of knowing for many years. She began working with children who have severe disabilities as a paraprofessional at Johnston Special School nine years ago. Maria was a Chapter I teacher aide before coming to Johnston but

immediately found her niche in special education. She resigned after two years with the school to pursue a degree in education with certification in special education. It was her goal to become a teacher of children who have severe disabilities. Maria earned her degree and was completing her second year of teaching when my field work began at Evansville. I looked forward to seeing her and renewing our friendship but was apprehensive about extending the research into her classroom. It was not a good time for Maria; she was returning to school after having been out for several weeks due to the tragic loss of her teenage son. Cognizant of her situation and the adjustments and changes in her life, it was only with Maria's approval and encouragement that I extended the study of Joy's life into her classroom. My "researcher self" would have preferred to make unannounced, extended visits, but my "human self" considered alleviating stressful situations for Maria to take precedence over the frequency and duration of the fieldwork. I explained if, on any occasion, I was in her classroom, and it was not a good day for her, that I would reschedule the visit at her convenience.

At the initial meeting with Maria and the principal to describe the research project, I explained that I was there to learn about Joy. I wanted to know what the day is like for her at school. Rather than determining if her program

worked, I was interested more in knowing how it worked. At the close of the meeting the principal made a comment that was perplexing to me: "Since you know Joy better, you should have some suggestions for us." Observer comments accompanying my field notes of the meeting reveal my puzzlement:

> Why would she think that I know Joy better? She has known Joy as long as I. Joy was at Johnston only 2 years when I left--and I haven't seen her in over 3 years! [The principal] has followed Joy's program for 6 consecutive years and attended her IEP meetings for the last 4 years. Why would I know Joy better than she?

On the morning that my field work at Evansville began, I arrived at the school, signed-in at the front desk, then went to Maria's room where several children in wheelchairs were being taken off buses and clustered near an entrance to the classroom. I scanned the room quickly hoping to get a glimpse of Joy. As Maria was pointing Joy out to me, I suddenly realized that she was one of the children a few feet in front of me facing another direction. As I approached Joy and kneeled in front of her chair to talk with her, the expressed concerns of her parents suddenly became a reality. Joy's head was dropped forward, and her right arm was tightly flexed close to her body. Her hands that once reached out to explore her environment and manipulate objects were held close to her chest, rotated slightly outward and limply bent at the wrists. Joy was drooling, a behavior I did not expect to see, and was

solemn and withdrawn. I spoke softly to her, then reached out to stroke one of her arms. Joy flinched as if she were not used to being touched. My thoughts were: "This is learned helplessness; Joy has become institutionalized." Her condition was a shock, a real blow. She was not the happy responsive interacting child I once knew. Lack of activation had apparently produced tragic mental debilitation and without the stimulating relationships she once enjoyed, Joy had chosen to retreat into the safe, protective inner world of the hypoactive.

Several months earlier I mentioned to Lorraine, Joy's former teacher at Johnston, that I was considering conducting a study of Joy's life. Lorraine hastily replied, "Oh my, have you seen her lately? Joy has changed...she's really changed. You ought to see her before you make that decision." Lorraine lives near the institution and frequently stops by to visit her former students. She seemed deeply concerned about Joy but did not go into any details about her condition. She lamented:

> It is so disappointing...so terribly disappointing. With a child like Joy it takes years to see the progress. We worked so hard to get her to the stage where she was ready to go into learning. She was beginning to show that she understands. She was making the connections. My first discovery was when she began to sing "ee-i-ee-i-oh." And, her book...her alphabet book! She really loved it! It was one of her favorite activities. I thought by recommending that she go to Evansville, Joy would really blossom. I never expected her to end up like this.

Encountering Joy for the first time in over three years, Lorraine's cautionary remarks came to mind, and I understood why Lorraine tried to discourage me from conducting a study of Joy's life. Her regression was disquieting. Most disturbing were the self-stimulatory behaviors Joy was exhibiting. Her elbows were bruised from banging them in rapid succession on the tray attached to her wheelchair. She was also swinging her head side-to-side in swift motion. When strapped in a corner chair, she often repeatedly thrusted her head and trunk backward in a bucking motion as if to signal that she wanted to get out of the chair or stand up. The powerful thrust of her body caused the chair to lift from the floor and jolt forward. The most distressing behavior was apparently due to loss of purposeful hand and arm movements. Without the use of her hands to explore, Joy had resorted to using her tongue to examine her surroundings. She frequently licked the surface of the tray attached to her wheelchair and when lying on the mat often lapped the carpet with her tongue.

A Typical Day

Though regular elementary children in Baylor District generally begin school at 8 a.m., Joy's bus, which transports only children with disabilities, does not arrive at Evansville until 20 minutes past 8 o'clock. She is met at the bus dock by a paraprofessional who assists in unloading Joy (while she is seated in her travel chair) off

the bus. Joy is then taken into the classroom where music is playing as part of the morning greeting. The first activity is to have her teeth brushed, which is followed by 30 minutes of music and a one-hour block of time for work toward IEP objectives. Considering the emphasis on positioning, most of Joy's IEP time is spent in a corner chair or her wheelchair. Other objectives are sometimes presented. Consider this example from my field notes:

> February 28, 1990, 9:38 a.m.
>
> Joy is in her wheelchair with her head dropped forward. On the tray attached to the chair is a tape player with a tape of Daniel, her brother, singing "Batman." Joy hears Daniel and starts to "sing." Sally [paraprofessional] sits in a chair in front of Joy and begins working with her on an objective to have Joy respond to different textures. Large cards with samples of different surface qualities (mostly fabrics) are presented to Joy. Placing the heel of her hand on Joy's forehead, Sally forces Joy's head back. Then taking Joy's hand she gently strokes it over a card saying, "You like the way it feels?" Joy's head drops forward, and Sally forces it up again. "Come on, feel it. Feel that Joy?" Joy's head drops forward, and she begins to grind her teeth. Guiding Joy's hand over the cards, Sally tells her, "That one is smooth, Joy. That one is rough. Feel it?" Joy's head remains dropped forward.

Around 10 o'clock Joy's diaper is changed, if needed, and she is placed on the mat until time for lunch. After eating lunch Joy is returned to the mat for nearly an hour of rest, and the lights are turned off in the classroom. After rest-time she is placed in the stander for 45 minutes. Next, a body awareness record is generally played and a paraprofessional or the teacher takes Joy and the other children through the motions of locating and patting

body parts as directed by the song. This activity may or may not, depending on time, be followed by 15 minutes of work on IEP objectives. Around 2 o'clock snacks are served. Joy rarely eats the pudding that is sometimes offered to her. Her diaper is changed around 2:30 and she is taken to the loading dock to be boarded onto a bus with a wheelchair lift and returned to Johnston. The paraprofessionals generally leave school each day by 3:00 p.m., but Ms. Lopez usually works until 3:15 or 3:30 p.m. to complete paperwork, including data forms and IEPs.

Setting aside the issue of a specialized curriculum, there are fundamental differences in Joy's school day when compared to typical 7-year-old children in Baylor District schools: Her bus arrives at school 20 minutes later and leaves 30 minutes earlier than buses for non-disabled children; unlike typical children who eat lunch in the school cafeteria, Joy's lunch is served in the classroom (there is, however, a large room adjacent to the kitchen that could be used for dining); though typical 7-year old children are not required to take naps, Joy must lie on a mat for nearly an hour of rest following lunch, during which time she is usually awake and "back-scooting" to move about; "recess" breaks are not taken outdoors but inside the classroom (Joy is generally lying on the mat); rather than using the rest room, Joy's toileting (diapering) occurs behind a partition at the back of the classroom;

though typical children are free to explore their school buildings and grounds, Joy's movement is restricted to her classroom, (exceptions are visits twice each week to the speech room and to the adapted physical education building, and an occasional trip to the PT room).

Separateness

Comparing the opportunities for the children in Ms. Lopez's PTU (as well as the other PTUs) to participate in school related events and activities with those of other children at Evansville, one is reminded of the policies and practices of tracking (Oakes, 1985). Children in PTUs represent the lower track and are denied opportunities for socialization and extra-curricula activities regularly afforded students at the school who are less physically and intellectually impaired. For example, unique off-campus programs and activities such as therapeutic horseback riding, adapted aquatics, and the special track and field competition are reserved only for the more able-bodied children. When asked about Joy's extra-curricular activities and field trips, Ms. Lopez replied that there were none. Children in PTUs do not attend community sponsored events, Special Olympics, nor do they go on field trips. Joy's teacher added, however, that she was allowed to take the children next door to the hospital grounds when clowns and circus performers were outdoors promoting the upcoming Shrine Circus. She also recalled that the

children were allowed to attend a pep rally at Evansville performed by cheerleaders from a local high school. Due to a recent federal mandate, plans were to bus some students from Evansville to a regular elementary school for one hour each day where they would probably eat lunch. Ms. Lopez expressed hope that Joy may be one of the children selected to participate, then imparted reluctant support of the proposed plan of integration: "We were told that we have to try it out. We've got to see if it will hurt our kids. I don't know...maybe not. It might even help."

"Joy Has to Prove Herself"

Meanwhile, I was finding myself in a difficult situation in the field. The Hamiltons were disgruntled with Joy's program and services and were continuing to make their concerns known to the staff. Dianne recounted an earlier visit that she and Robert made to the school:

> I told them I want Joy's program to be harder. She's bored, and we keep telling them all the things she used to do. But, they don't believe us. I went in there--I think it must've been the PT room--and Joy was in shorts on the mat. I told that therapist it wasn't right to put Joy on the cold mat without a blanket. Would she lay her child down there like that? I had to tell her about Joy's arm being tighter. She checked it and said it was about the same, but I told her it wasn't! Joy's arm was getting tighter and tighter. Finally, she agreed but said the reason I could see it and they couldn't was because they are with her every day! They said I could see it before them because I don't see her as often. I could've choked her. She's the therapist, not me. She should've seen Joy's arm drawing up. It's like they don't care. They're not going to do anything unless the parent raises a fuss. Then she tells me Joy "wears her out." All she did was complain about Joy and having to work with her. I wanted to tell

her, "If you don't like working with children like Joy, you ought to quit your job." She gets paid to help my child and if she doesn't like helping Joy and these others, she ought to quit work. I told her I wanted Joy in a walker, and she said it wouldn't be good for her. Then, it was lunch time. I wanted to feed Joy. They brought in this tray of food, and I tasted it before I fed it to her. And, it was as cold as it could be. You know, I don't want to hurt anybody's feelings, but I'm tired of the way they do things. And, I'm mad 'cause it's not good for Joy. Would they feed their child cold food like that? I just told that lady, I said, "Look, this food is cold. I don't want to feed it to her like this. Can you warm it?" I felt bad for the other children 'cause they were fed the same cold stuff. You know, dead people are treated better than Joy is. I know this lady. She's a beautician and she has to fix the hair on the corpses in funeral homes. And she won't wash the [deceased] person's hair in cold water. No, she told them she needed warm water. It's not right to put cold water on a body like that. It seems like the dead get more respect than children like Joy. Why can't people respect them...They're not dead...They're alive!

Robert remarked with annoynance:

They just don't have much for Joy to do. There's not that many toys and things. I kinda got mad when they put Joy in her wheelchair cause they said it was time for her to go to therapy, and then let her sit there doing nothing for nearly an hour! Finally, I said, "Well, when does she go to P.T.?" And, when they told me it wasn't till 1:00, I said, "Well, I'm not gonna let her sit there that long and do nothing." I unstrapped her and took her out of her chair, and put her on the mat, and played with her. We thought about it, and there's not one good thing, really not one good thing about her program!

Recalling Joy's program at Johnston, Diane commented:

You know what we miss the most? Remember how Lorraine and Judy and Pam [teacher and paraprofessionals] used to get so excited about things Joy was doin'? I mean they'd meet us at the door. We couldn't get inside the building hardly, and they couldn't wait to tell us what Joy was doin'. There's none of that anymore. Ya'll used to act like fools--you know what I mean? Just go crazy. You were so happy when Joy learned something. There's none of that now. It's so...so

> depressing. I keep telling her teacher to call Lorraine. They just don't believe us. They just don't know how to reach Joy. What makes me mad is Joy has to prove herself.

Robert continued, "Tell her about what happened when we walked into Joy's room."

Diane described the event:

> When we walked in, Joy was sittin' there so pitiful. And, we walked in, and she heard us. And she picked her head up and started singing and kicking like she always does. She was so happy we were there. She started singing "Batman" with Daniel. And, her teacher says, "Well, she's done more for you than she's done for me all year."

A Fragmented Approach

The most striking contrast between Joy's program at Johnston and that at Evansville was the lack of collaboration in planning, implementation, and evaluation. The therapists worked in isolation from the classroom teacher in a pull-out program. The children were removed from their classrooms and taken to isolated areas for therapy. Evidence of a fragmented program is illustrated in two teaching situations. The first involves a speech therapy session in which Joy was to choose between music and a battery operated toy by activating two switches. Joy's hand was rotated, and rather than pressing the switch with an open hand, she was unsuccessfully banging the switch with her wrist. The OT, however, working in consultation with the speech therapist, could have assisted the speech therapist in adjusting the plate switch to a

slanted position and demonstrated ways to encourage Joy to press the switch with an open hand. Another example is found in Joy's adapted physical education program. The PT in consultation with the adapted physical education teacher could have assisted the teacher in finding ways to encourage Joy to propel herself on the scooter board lying on her stomach. The scooter board, as it was used in her adapted physical education class, with Joy on her back and forcing her heels against the floor, caused her body to go into full extension; an abnormal posture, which should have been avoided. Without collaboration of persons responsible for Joy's education across all areas, her program was fragmented and produced behaviors that impeded progress.

As the Hamiltons continued to voice their concerns about Joy's program, Maria approached me and asked for suggestions. Joy was "a puzzle, a mystery," to use Maria's expression, and she had tried everything she knew to enhance Joy's program. Her annual IEP conference was scheduled for the following month and Maria was open to ideas or suggestions to improve Joy's program. I would have preferred to maintain a less involved role in the research. After wrestling with the thought for several weeks, however, I decided that it was my professional obligation not only to Joy but to her teacher and to her parents to assist. Because the suggestions focused on a collaborative effort of the education team, I met with the

principal and Maria to discuss possibilities. (An excerpt of the letter regarding this conference is found in Appendix E.)

The Hamiltons were persistent about a walker for Joy and made an appointment at Shriners' to have her evaluated by an OT and a PT. Some of the suggestions mentioned in the conference with the principal and Maria surfaced in the report from Shriners' : weight-bearing to improve head control, encouragment of vocalizations, vestibular ball exercises, and a walker for brief periods twice a day. Elbow and hand splints were also recommended. Noteworthy was the recommendation for direct PT and OT services 45 minutes twice each week. (See Appendix F for recommendations from Shriners' .)

Despite the evaluation from Shriners' with orders signed by the pediatric orthopedist, the physical therapist at Evansville refused to put Joy in a walker for brief periods each day, stating that if Joy were to use a walker, it would not be under her supervision or a part of Joy' s PT program.

Joy' s annual IEP conference was held April 14, 1990. Although the habilitation staff seemingly had not participated in Joy' s IEP since she was transferred to Evansville two years before (according to education records), it was well represented at this conference with three persons from the institution present. The Hamiltons

came to the conference with a prepared list of concerns and recommendations (see Appendix G). Personal bias surfaced when I walked into the conference room and saw so many persons from the habilitation staff present. Consider my observer comment notes:

> April 14, 1990
>
> If the IEPs and special education center's records are accurate, and no one from Johnston has attended Joy's IEP conferences in the two years that she has been at Evansville, why are they here now...at <u>this</u> IEP conference? Could the research project that I am conducting have anything to do with their being here today? If this study were not being conducted, would they have attended the conference?

Maria stated that she had collected information from several sources including Joy's previous teacher, Shriners', the suggestions I offered and her own observations of Joy. Following the conference Maria wrote a detailed and comprehensive IEP that markedly contrasted with Joy's previous IEPs at Evansville. Examples of activities include reaching for toys in a pan of water, pulling forward on a scooter board, rolling a ball, kicking a ball while in the walker (to encourage reciprocal movement), holding a spoon with assistance and bringing it to her mouth, holding a cup with assistance as she drinks, interacting with a computer and peers by turn-taking, activating toys, choosing a preferred toy by activating a switch, and verbalizing for objects and people. In addition physical therapy objectives include activities to improve Joy's head control, to improve weight-bearing on

her feet (while leaning against a large vestibular ball), as well as to improve range of motion in arms and legs. Occupational therapy goals are disappointingly very similar to Joy's last 2 IEPs and focus on tolerating placement. Wearing of hand and elbow splints, however, is mentioned. Noteworthy are the related services that are added to Joy's IEP. Rather than consultative services, she was to receive direct PT 30 minutes each week and direct OT 30 minutes each month. Although Shriners' recommended a more aggressive program (45 minutes of OT and PT twice each week), the parents were reasonable and willing to compromise due to a shortage of therapists in the school system. Joy was to also have an Extended School Year Program, and to have lunch and recess with nondisabled peers two times a month.

Maria, Joy's teacher, had been making noticeable changes in Joy's program prior to the conference. She was working with Joy on a computer program that allowed her to make choices, had Joy placed in a music class with children who were vocal, and was putting her in the walker. She met me as I walked into the classroom one day and with excitement exclaimed, "Joy went to the water fountain in her walker and drank some water [as the paraprofessional pressed the lever]. Then, she saw light coming through the window in the backdoor and said "oŭ-si" [outside] 4 times!"

As Maria and Joy changed there was a noticeable rippling effect in the other children's programs in the class. For example, although no children were using walkers before Joy began to use her's, another student was now also using one. Maria seemed more enthusiastic about her class and the activities they were attempting and accomplishing. She also expressed a desire to revise her method of collecting data and mentioned, in particular, the data record form.

Initially Maria perceived the Hamiltons to be unrealistic in their expectations for Joy. When they encouraged her to review Joy's previous IEPs, Maria confided to me that she did not see "much difference" between her IEP at Evansville and the one at Johnston. As the school year ended and Maria glanced back over the past months, her words eloquently expressed a transformation of her beliefs:

> Joy was definitely withdrawn into herself. I had no idea that there was something there. I had no idea that she was capable. It's a sad thing when these children can't talk. They can't tell you "I'm bored" or "This isn't me." My expectations for her just weren't there. We [she and the paraprofessionals] didn't know. But, when her parents visited that time and I saw how Joy reacted to them, I know there was a lot more to Joy than I thought. That's when I said to myself, there's a key somewhere to this puzzle. I talked with Joy's teacher of the previous year [at Evansville], but that wasn't much help. The parents kept telling me to call Lorraine. Finally, I said, "I've got to call her." And when I did, and Lorraine told me some of the things Joy was doing, I said to

myself, "We're going backwards." That's when I started expecting more of Joy. I knew there was more to her. And when I expected more, I got more. I knew her better and got a more complete picture of her...There *is* a lot more to Joy!

CHAPTER VII

THEMES OF A TRANSFORMATIVE CURRICULUM IN THE LIFE OF JOY

> *The participants part from one another has changed beings. The individual perspectives with which they entered upon the discussion have been transformed, and so they are transformed themselves.*
> *--Hans-Georg Gadamer (1981, p.110)*

The original questions directing this study of how curriculum has affected the life of Joy Hamilton focused on the differences between her preschool and her early elementary programs. This chapter will reiterate the study' s findings and place them within the broader context of the alternative approaches to education proposed by Heshusius and Doll. I begin by revisiting the assumptions of their proposed models.

Heshusius (1989) offers an alterative approach to special education situated within the world view of reality that is undergoing change across the sciences and social sciences. Arguing for a shift away from the mechanistic paradigm that has dominated the concept of reality for centuries, Heshusius proposes a resurrection of the holistic paradigm as the one by which we should self-consciously live. The author offers the following translations of the holistic paradigm into educational principles: learning is understanding relations rather than pieces of knowledge; the process is transformative, rather than additive and incremental; there is no one best way to teach or assess;

assessment focuses on what students do over time in engagements purposeful to the student in natural, interactive settings; and possibilities and choices are essential in a curriculum for human learning.

Similarly, Doll (1988) provides the critical link between the mechanistic paradigm and the K-12 curriculum in American schools and offers an alternative transformative curriculum. Rather than a pre-set order which precedes instruction, curriculum is redefined as "the process we engage in when we teach and learn with our students" (p. 130). In contrast to the "measured" curriculum, a transformative curriculum is open to change, filled with dialogue, not pre-set with goals, and emergent from interaction. It is a process that views learning as a self-organizing construction of relations which occurs at bifurcation points where irreversible transformations take place and new vistas for learning emerge. Transformative assumptions transpose the incremental and linear sequencing of the measured curriculum with a developmental or spiral continuum punctuated by spurts, plateaus and regressions of internal levels of competence.

Doll's transformative curriculum is delineated by the following elements: the *richness* of the multiple possibilities of interpretations that emerge in the process of teaching and learning with our students; the *recursive reflection* of having thoughts loop back on themselves; an

emphasis on pedagogical and cultural *relations* for meaningful, interactive dialogues; and, the *rigor* of combining the complexity of indeterminacy with the hermeneutics of interpretation.

The essence of the arguments of these and other scholars advocating an alternative approach to education lies in understanding how knowledge is constructed both individually and communally. Consequently, the tenets of Heshusius' alternative holistic model of special education and the principles of Doll's transformative curriculum partly overlap. Therefore, I draw upon the principles of both approaches to discuss the issues that emerged in Joy's life history. First, however, because it is fundamental to issues regarding her education, I discuss the ethos of the schools Joy attended.

Ethos of the Schools

Probing beyond the written philosophies of both schools to understand what the process of educating Joy meant to those involved, reveals a subtle distinction between the beliefs that guided the two programs. Evansville Special School has origins deeply rooted in a medical model aimed primarily at therapeutic intervention for children who have orthopedic impairments. To that end, a clinical approach is deeply ingrained in the unwritten philosophy of the school and guides the decisions of those, particularly the therapists, required to provide services to the newcomers:

the children who have severe multiple disabilities. Change is very difficult for the school as the principalship has been handed down for nearly forty years to persons on the staff "groomed" for the position to carry-on with the schools traditional values and beliefs. There is a tacit perspective of education for children who have severe multiple disabilities that is seemingly rooted in a charity ideology; one which views the school as providing a community service by accommodating this population of children. It is a perspective that assumes that the children's disabilities are the most salient feature of their identities. Such a view is reflected in the reduction of related services and the passivity of their IEPs, the separateness of these children from the more able-bodied children in the school, and their restricted participation in school outings and functions.

The origin of Johnston Special School sharply contrasts with that of Evansville. Organized in 1981 as a result of EAHCA, its purpose was to provide appropriate special education and related services to all individuals up to the age of 22 living at the institution. Unlike Evansville Johnston Special School reflected a perspective of education based on disability rights issues. Whereas providing education for children with severe multiple disabilities was forced upon the staff at Evansville, it was the choice of those at Johnston to serve this population. The school's

staff did not have to wrestle with conflicting assumptions, values, and attitudes among themselves. Instead they brought a fresh and cohesive perspective regarding the education of the students with them and were open to learning and to change. Nonetheless, a clash of deep philosophical differences between the medical model of the institution and the holistic model of the education program eventually led to the closure of the special school.

The ethos of the two schools--a perspective rooted in charity ideology at Evansville and a perspective reflecting disability rights at Johnston--had a decided impact on the educational programs provided for Joy at each school. The following themes evolved partially from the nature of the research data, partially from the theoretical framework regarding my concerns about special education for children who have severe disabilities, and partially from the principles of holistic and transformative education espoused by Heshusius and Doll.

Theme One: The IEP is Something to Revise, Not Something to Follow

The IEP is the keystone of the IDEA. As a document it is a necessary component intended to carry into implementation the egalitarian view of providing an appropriate education for children and youth with disabilities. It is considered a critical element from which to monitor and enforce the law. As a process the IEP

is a blueprint for instruction, a guide for planning that reflects the quality of a child's education.

Heshusius (1982) maintains that the mechanistic view of reality sees the student as a reactive/passive organism. Evidence in Joy's IEP developed by the staff at Evansville strongly reflects such a perception. It prescribes a rigidity in the teaching-learning process aimed at predicting and controlling Joy's behavior with little or no regard to self-organizing or inner goal-directedness. An emphasis on conditioning revealed in passive goals and objectives aimed at having Joy *maintain* positioning and *tolerate* sensory stimulation appeared to be at the expense of the cognitive and emotional aspects of her development. With little guidance and opportunity for Joy to reflect and think and act on her environment, opportunities and possibilities for growth seemingly go unnoticed.

That which is missing in the Evansville IEP was taken up in Joy's IEP from Johnston. The staff was focused on objectives and goals aimed at activeness that involved Joy's personal creation of meaning as she learned to participate in her environment. Joy actively constructed and transformed reality in the choices she made. Attention to Joy's autonomous purposefulness and inner mean-making was revealed in the comments of the staff as documented in staffing reports. The staff often changed direction, modified instruction, and adapted objectives according to

their interpretation of Joy's response. Action took a commanding lead in the wording of Joy's objectives; Joy combines, removes, drops, picks up, retrieves, touches, expresses, places, dips, plays, finds, indicates, interacts, interplays, and offers.

Rather than regarding the IEP as a document to command the instructional program, the IEP was perceived as a *process* with a working document to be continuously revised and updated to reflect modification and adaptation of Joy's program in accordance with the staff's insights and judgment gleaned from Joy's interactions. The staff, therefore, came closer to being reflective practitioners than executors of a prescription of IEP goals and objectives.

Theme Two: Learning is Understanding Relations

There were subtle references in Joy's program at Johnston that seemingly reflected learning as understanding relations rather than mastering bits and pieces of knowledge. For example, when providing opportunities for Joy to experience the feel of different textures, emphasis was placed on having her feel and manipulate objects in the context of her classroom. According to data record forms, Joy was encouraged to feel the soft blanket to signal nap time, to feel her food, her clothing, the clothing of others, the carpet, the curtains, the walls, the windows, and various toys and other objects in the classroom. In addition, opportunities were provided for Joy to explore the

texture of another person's hair, skin, hands, and facial features. When outside in her walker Joy was free to explore and was assisted to feel the textures of natural elements she came in contact with such as the bark on a tree, a leaf, grass, and stones.

On the other hand, an attempt to have Joy respond to different textures by feeling samples of fabric and wall paper attached to cards (as presented in her program at Evansville) is an indication of isolated skill training that implies a view of learning acquired through bits and pieces of knowledge.

Theme Three: Each Child Is An Individual; There Is No One Best Way To Teach

Team work and collaboration with other persons responsible for the child's growth and development is the cornerstone of a transformative process of learning for a child who has severe disabilities. As the pediatrician endorsing the Photo Essay concept so eloquently stated, "Each child is an individual and what is good for one child may not be good for another." Collaboration is not something that occurs once a year at an annual IEP conference, but is a process that is on-going in the continuous revising and updating of a child's program as changes--even the most minute changes--in the child are observed. Collaboration opens the door for new experiences and possibilities for learning. Often in educating children who have severe disabilities, professionals encounter

situations that require careful consideration of the pros and cons of activities for a particular child. When the decision requires a "trade-off" it is critical that the professionals representing each area of expertise work together to arrive at the best solution for an individual child. A mutual awareness of each team member's role and responsibilities is important. Vested interest in professional roles must not take precedence over what is best for the whole child. I use an example in Joy's case to illustrate this point. Experts in the field guard against bouncing children who have cerebral palsy on the balls of their feet as this can cause abnormal posturing. At a staffing the pros and cons of placing Joy in a bouncer were considered, and the staff decided that in Joy's situation the advantages outweighed the disadvantages. Joy's body did not always go into full extension when she was in the bouncer (evidence supporting this observation is found in her photo essay). The purpose of placing Joy in the bouncer was more for her enjoyment, for the sensation of being suspended upright in a standing position, and to have her self-direct her body movements as she put one foot on the floor to turn her body from side-to-side, to slowly spin, and to stop movement. This activity also permitted Joy, as "door-keeper," to experience the movement of persons entering and leaving the classroom and thus provided additional opportunities for spontaneous interaction with

adults. In addition, Joy was able to "monitor" activities and conversations of other persons in the hall, and being in the center of the movement and conversation is something the staff observed to be pleasurable for Joy.

Theme Four: Evaluation is Collaborative and Focuses on Qualitative Changes Over Time

Doll's (in press) and Heshusius' (1989) alternative approaches emphasize evaluation as a communal process which assesses qualitative changes over time. Similarly, in Joy's program at Johnston, there appeared to be less emphasis on counting and ranking correct responses to controlled tasks than documenting and assessing Joy's real life processes and accomplishments. This is evidenced by the data record forms which often described shades of qualitative changes in Joy (as well as the adult working with her), in addition to the usual record of the number of trials. Another indication supporting the staff's emphasis on qualitative changes over time is found in the general descriptions of Joy in her IEPs.

Evaluation of the progress of a child who has severe multiple disabilities is a collaborative effort involving the educational team, including the viewpoints of parents and families. As Sailor, Gee, Goetz, and Graham (1988) remind us, the inclusion of valued educational outcomes from the perspectives of families is essential in determining the success of our efforts in educating children who have severe disabilities. Evidence that Joy's parents were included as

collaborators in assessing Joy's progress is found in some of the staffing reports from Johnston.

Theme Five: The Process of Learning is Transformative

Heshusius (1989) tells us that holistic assumptions view the process of learning as transformative rather than additive and incremental. Doll (1988) likewise points to the most important aspect of the learning process as the qualitative changes at bifurcation points where irreversible transformations take place and new vistas for learning emerge. Consequently, transformation requires a recursive dialogue between the teacher and the child. For a transformative process of learning to occur, a holistic approach seeks to understand the "innermost beings" of a child. Keenly attuned to the subtle exchanges of a child with her or his environment, the holistic teacher recognizes what is happening "inside" the child and transforms teacher input accordingly. In contrast to the standard and fixed aims and outcomes of the mechanistic approach now in place, the holistic approach must be flexible and permit a teacher with a holistic vision to interpret learning and educational achievements as newly created within particular contexts of time and place (Iano, 1989).

How may a teacher probe deeply within the world of a child who has severe disabilities to understand her or his "innermost beings"? One avenue lies in the work of Doll (in press), who proposes a new frame for rigor in a

transformative curriculum, which combines the complexity of indeterminacy with the hermeneutics of interpretation. Rigor refers to the conscious attempt to uncover or disclose often hidden assumptions, ones we or others hold dear, so the dialogue may be meaningful and transformative. Indeterminacy "allows for a range of possibilities from which actualizations appear" (p. 46). Hence, the rigor of combining indeterminacy with interpretation produces a rich interpretation dependent on how thoroughly we develop the alternatives presented by indeterminacy.

Theme Six: Philosophical Hermeneutics, an Avenue for Interpretative Understanding

The problem of understanding the innermost beings of a child who has severe disabilities, particularly one who is nonverbal, is an extremely complex process. Acute attention to and reflexive interpretation of the child's responses and environmental exchanges, including subtle and overt gestures, utterances, facial expressions, and body movements are keys to understanding what is happening "inside" the child. How these responses and interactions are interpreted lies in the vast horizons of hermeneutics, which can immensely expand the thought of and deeply enrich the practice of special education. Loosely defined as the theory or philosophy of the interpretation of meaning, hermeneutics has its origin in the ancient art of interpreting meanings in sacred texts. A revival of interest in hermeneutics has played a major role in debates

and reformulation of the human sciences. Today social scientists must know how participants themselves interpret their practices and actions in order that they, the researchers, may know the meanings of the social practices that are the object of their research. This prior step of understanding the participant is precluded in traditional natural science research (Bleicher, 1980). Consider the part played by interpretive understanding in teaching children who have severe disabilities. The teacher does not regard the children merely as severely handicapped individuals but considers them as individuals, each with a temperament and individuality, for whom responsibility and affection is felt. The teacher seeks to respond to the child's Being, a "light," according to Heidegger (1977, p. 175), in which things are revealed as they actually are. To be aware of the child's Being, to live consciously in its presence, and to have the child sense that nothing in his life matters more than his relation to Being is the teacher's duty (Murray, 1978). Knowing that a child who has severe disabilities cannot communicate in conventional ways to question and answer discussions, the teacher seeks to understand the child's Being by interpreting the meaning of the child's responses and exchanges with her or his environment, including her or his most subtle movements. This interpretative understanding allows the inaudible voice of the child who has severe disabilities to be heard.

Doll (in press) tells us recursive reflection is at the heart of a transformative curriculum. Recursive reflection in "dialogue" manifests itself in a teaching situation with a child who has severe disabilities when the child with a limited repertoire of responses and the teacher with an unlimited view of the child' s Being reach an understanding they had not anticipated. Because "dialogue" proceeds through questioning and answering the meaning of a child' s response and adjusting input accordingly, the responsibility for its occurrence rests squarely upon the teacher. Despite a fixed IEP objective, consider how "dialogue" emerges in the following example of teaching a social-emotional skill. The objective states the behavior, how it is to be taught, how it is to be evaluated, and what the fixed expected outcome is to be: "Positioned in a floor-sitter and given an interactive play situation (peek-a-boo or patty-cake with a caregiver) the child will smile 3 times within a 5 minute period on 2 consecutive days." Knowing that the fun of playing must be taught by and caught from the teacher, repeated attempts are made to elicit a smile from the child while playing the games. The child startles, frowns, and cries. Correcting a preconception about the child as being unsociable and having a disdain for interaction with others is revealed during the "dialogue." The teacher, open to new understandings, questions and seeks answers to why the child responded negatively. Was the activity too noisy? Were the

movements too abrupt? Is the child comfortable? Adjusting her strategy, the teacher lifts the child from the floor sitter and, affectionately holding the child in her lap, proceeds to prompt the child through the motions of patty-cake. The child smiles and signals by hand movements that he wants the interaction to continue. Abandoned preconceptions free the mind for a wider view. The child begins to feel unthreatened while the teacher discovers that the child is even more complex and surprising than previously thought. Mental horizons converge as the child and the teacher bring a new mind-set to the experience. The child discovers pleasure in an activity that once was frightening. The teacher recognizes that this child needs close personal contact and cuddling even with a familiar person to enjoy interactive play. The teacher and the child part from one another as changed beings. Their perspectives with which they entered into the dialogue have been transformed, and so they are transformed themselves. Their insights, however, are tentative since any activity is open to many interpretations, and these interpretations reflect the teacher's and the child's present horizons and their moment in history.

The ontological task of hermeneutics involves faith. The teacher has faith in the possibilities for learning that lie beyond the stable ordered curriculum for children who have severe disabilities, and acts on that faith. For the

teacher of children who have severe disabilities, understanding the whole child comes from interpreting the most subtle body language. A momentary eye gaze, the flickering of an eyelid, a slight turning of the head, a barely audible guttural utterance, a slight movement of an arm or fingers, random eye movement, as well as whole body movement are ways in which a child who has severe disabilities may be communicating likes and dislikes, desires and disdain, and preferences for choices.

Volitional body movements like these that occur in natural settings, however, often go unnoticed by traditional teachers and are regarded with little significance unless the movement is a specified behavior to be measured by an IEP objective. Consider this objective from a child's IEP: "Given the ringing of a bell, [the child] will turn to the direction of the sound 2 out of 3 times for 3 consecutive days." The volitional movement of the child is interpreted as a response or interaction and acted upon accordingly in a staged situation. More appropriate is the child's response in a natural setting. For example, when the classroom door is opened, does the child indicate by even the most subtle body movement that he is aware of the direction of the noise?

A teacher guided by holistic principles seeks to understand a child who has severe disabilities in a way that volitional movements may be distinguished from reflexive,

involuntary movement. This comes from knowing the whole child with particular attention to physical health. For example, eye gaze, rapid flickering of the eyelids, and lip smacking by a child who experiences absence seizures should not be read as anything more than involuntary movement characteristic of the seizure disorder.

How are holistic or transformative principles that postulate free expression of self-organization, inner mean-making, and inner goal-directedness manifested in the education of children who have severe disabilities? Drawing upon the most subtle volitional movement, a holistic teacher seeks to understand the child's likes and dislikes and provides opportunities for the child to signal her or his preferences and make choices. The teacher responds to her or his understanding of what the child is trying to tell, establishing a true dialogical relationship to the fullest extent possible. The impulse to learn and to self-organize through goal-directedness can then take place in children who have severe disabilities. Consider the example of a meal-time situation which is an integral component of the self-help skills that must be taught to most children who have severe disabilities: As the paraprofessional lifts a spoonful of rice to Joy's mouth, she turns her head away from the spoon. After several failed attempts to have Joy accept the food from the spoon, the paraprofessional, assuming that the Joy has no regard for the feeding

situation and considering that hours have lapsed since the her last meal, puts more emphasis on the nutritional rather than the learning aspect of eating. Placing the heel of one hand on Joy's forehead and forcing the her head backward and her mouth open, the paraprofessional begins to force feed Joy. In contrast to this response, a holistic perspective seeks to understand what Joy is communicating as she turns away from the spoon. Does she sense the food is too hot? Is the aroma of the rice not appetizing? Could she be more thirsty than hungry? Is Joy not feeling well? Does she not like rice? Or, is Joy simply not hungry? Seeking to understand Joy's response, the paraprofessional adjusts input. She may raise a glass of milk to one side of Joy's face and offer a spoonful of meat to the other side, allowing an opportunity for Joy to indicate preference for food or drink by turning to the direction of her choice. Presenting a choice acts on the premise that the child's inner goal-directedness is a primary characteristic of human life and learning. Unlike traditional approaches that have little or no regard for a child who has severe disabilities to make choices or show preferences, a holistic approach believes and acts upon the belief that these children should be given choices in every aspect of their instructional program and that teacher input should be adjusted according to choices the children make.

Another example that brings to bear the importance of a reflective, empathetic approach to interpret the innermost being of a child is situated in Joy's classroom about thirty minutes following lunch. It is rest time, and the children are asleep on mats with the exception of Joy who is lying down but continuously rocking side-to-side. Slowly scooting off the mat, Joy extends her body in the direction of the teacher, who is seated at her desk, and scoots on her back until she is at the side of the teacher's desk. Oblivious to any message Joy may be communicating, the teacher lifts Joy off the floor and returns her to the mat commenting that she would like for Joy to stay put at nap time because she disturbs the other children. Her teacher is also fearful that Joy may injure herself by bumping into a desk or chair. In contrast to this response to Joy's scooting across the classroom, which the teacher regards as habitual self-stimulatory behavior, the holistic teacher questions why Joy chose to move about the room. Since rolling and back-scooting are the only means of independent locomotion for her, could Joy's motivation to move near the teacher be to initiate interaction? Was Joy trying to get her teacher's attention? Is it possible that Joy, having formed a cognitive map of a path to the teacher, was successful in carrying out a schematic plan to get the teacher to notice her?

A holistic or transformative approach indeed adds humanness and dignity to the lives of children and seemingly would be the model of choice for educators and administrators. The approach, however, with the possibilities for growth that it holds, can bring about major conflicts within a system that demands mechanistic practices. A teacher guided by holistic principles does not confine the educational experiences of her children to a pre-determined set of objectives contained in prepackaged curricula, curriculum based assessments, or developmental tests that require the linear, orderly acquisition of one skill before another is introduced. Preferring teacher autonomy as well as intuition, judgment, and the children's transactions to determine curricula decisions, the holistic teacher engages in the art of teaching, operating within the limits, but not controlled by the mechanistic practices inherent in special education policies and procedures. Serious conflict, nonetheless, emerges as illustrated in the example of Joy's former teacher who is guided by holistic tenets as she goes about the task of educating the children in her present classroom. The six preschool children in her room have, according to psychological testing, "severe or profound mental impairment." All are ambulatory, some have limited conversational speech, and others have verbal skills that are emerging. Lorraine is not bound by the labels attached to the children, and recognizes the potential to

learn in each child. She seeks to provide many opportunities for the children to learn, based upon their preferences, that extend beyond the range of the linear ordered curriculum which she is required to use with these particular children. Concrete objects have been used to introduce labeling of objects. For example, an actual chair is used to teach the concept of chair as an object to sit on. Lorraine notices, however, that when given pictures of animals, objects, and other children, curiosity and conversation emerge naturally. The children seem to enjoy talking about the colors and shapes and counting the objects in the array of pictures and the collection of children's books that she provides to stimulate conversation. Serious problems emerge when the supervisor of the program, who places an enormous trust in the assessment results and prepackaged curricula for preschool children who have disabilities, requires that Lorraine remove the pictures from the classroom, that she use only concrete contextual objects to stimulate language, and demands that she work only in one-on-one situations with the children. "No more group activities," Lorraine is told. Criticizing her for having poor judgment in assessing the functional levels of the children and for using materials and activities that are 12 to 18 months above their measured intellectual ability, the supervisor warns that Lorraine's approach is frustrating to the children and if continued will cause the children to

become emotionally disturbed. Criticizing her also for providing opportunities for the children to paint and color, the supervisor states that the children do not possess the prerequisite skills for these activities. Lorraine, who is face-to-face with the children day in and day out and who provides these opportunities to allow the creative and aesthetic dimensions of the children' s beings to emerge, believes differently. The supervisor leaves the classroom, emphatically stating that she does not want to see the pictures in the room again.

Lorraine, struggling to survive within a system that mandates mechanistic educational practices and believing there is learning beyond such practices, instructs her paraprofessionals to readjust what they are doing when they are aware that the supervisor is approaching the room. They hasten to recreate the learning experience with the mundane, repetitive stimulus-response objectives that Lorraine regards as little more than babysitting these children. But when the supervisor leaves the room and the door closes behind her, the teacher reports that out come the pictures, the books, the paints, and a dialogue emerges...and the learning begins! Behind the classroom door concealed from the critical surveillance of the supervisor, the joy and the art of teaching is resurrected. The supervisor criticizes the teacher and singles her out as the "most ineffective teacher" at the school for not controlling her students, for

failing to follow precisely the prescribed curriculum, and for refusing to abide faithfully by the assessment data. Yet, by concentrating less on these mechanistic practices and more on adapting her instruction according to interpretive understandings of the children's responses, Lorraine perhaps comes closer to the heart of education than all the others.

Impressions

The life story presented here reveals issues related to an alternative approach for the education of children who have severe multiple disabilities. One important theme is that the teacher-student relationship helps determine the experiences, and therefore, the opportunities to learn. Joy's educational experiences help further illustrate that the interactions and relationships of all persons responsible for the growth and care of a child who has severe disabilities will determine the way the child will function, including how the child perceives herself or himself, and the extent to which the child will be able to act on her or his environment.

Analyzing the past and present educational experiences of Joy's life reveals that the limitations of our mechanistic beliefs have been reached; the traditional measured curriculum is outmoded. The discoveries of the study presented in the final chapter uphold the arguments by Heshusius, Doll, and other scholars in the field calling for

an alternative approach to education. Moreover, the findings point to the transforming effects of a holistic process of learning with layers of richness, reflective recursion, relations, and the rigor of hermeneutical interpretation as the degree or quality of difference that made a difference in the life of Joy Hamilton.

CHAPTER VIII

RE-REFLECTIONS

> *What the best and wisest parent wants for his [or her] own child, that must the community want for all of its children. Any other ideal for our schools is narrow and unlovely; acted upon, it destroys our democracy.*
>
> *--John Dewey (1899/1959 p.34)*

As the story of Joy's life talks back, I listen, and appreciate what I hear, and reframe the situation once again (Schon, 1983). Thus far, I have remained close to the works of Heshusius and Doll in my analysis of how curriculum has affected Joy's life. The first section of this chapter aims to expand the discussion beyond special education, enlarging the frame of reference to education in general. The second section returns to critical perspectives of special education from scholars (other than Heshusius) concerned about educational reform. For now I turn to a substantial body of literature that challenges education's traditional mechanistic model and draw a line of connection between Joy's story and four prominent thinkers whose works inform us about education: Foucault, Vygotsky, Freire, and Gadamer.

Foucault, according to Dreyfus and Rabinow (1982), argued that oppression is inscribed in the neglected histories of the poor and humble. His work was to recover,

through a method of archeology or genealogy, the history of ideas (rationality) and of institutional power and to show their interconnections. Consequently, Foucault's search was for the discursive formations which construct and constitute reality. In writing concrete histories of the practices and discourse of the social sciences and professions, Foucault (1980) probed for two kinds of knowledge: one that has been "buried and disguised in a functionalist coherence or formal systemisation" (p. 81) (such as alternative perspectives that are distorted and hidden by the dominant mechanistic paradigm); and another "disqualified knowledge" (p. 82) of the marginalized who are subjugated to the normalizing discourses of professions. Foucault argued that the surface practices of the social sciences and the techniques, procedures, surveillance, exclusion, confinement, and medicalization that professions employ are infinitesimal mechanisms of power extended to control and discipline populations. Foucault's analysis of institutional culture manifests itself in the life history of Joy. We see interpretations of an alternative holistic approach to education (Johnston Special School), which theoretically critiques the grounding assumptions of the dominant mechanistic model, aggressively attacked and eventually buried by a medical model (the institution) that espouses traditional practices. Additionally, Joy's life history unearths a "disqualified knowledge," an understanding of a

child at the edge, the extreme of social life, exiled, and physically marginalized through placement in an institution and in a special school. Her life on the edge of the social map (see Ferguson, Ferguson, & Taylor, 1992) is likewise preserved in the practices and discourses of the professions responsible for her care and development.

Vygotsky's (1978) contribution to education was a historical-cultural approach which viewed learning not as an additive and incremental process, but rather "a complex dialectical process, characterized by periodicity, unevenness in the development of different, metamorphosis or qualitative transformation of one form into another intertwining of external and internal factors, and adaptive processes" (p.73). Vygotsky's conceptualization of development rejected the assumption of linear development and incorporated a dialectical process of learning that is socially constructed. In contrast to programmed and frequently mechanized instruction, Vygotsky viewed learning as a profoundly social process of cultural transformations. Similarly, Vygotsky's view of learning speaks through the voices of Heshusius (1989) and Doll (1988) who develop the concepts of a holistic model and a transformative curriculum to offer alternatives to traditional educational practices.

An original application of Vygotsky's principles is found in Paolo Freire's, *Pedagogy of the Oppressed* (1970b), a story of class differences and literacy campaigns in Third

World countries. Freire modifies his educational practices to the specific historical and cultural settings in which illiterate peasants live, enabling them to combine their "spontaneous" concepts based on social practice with those introduced by teachers. Freire's work indicates the role of community members and student voice in a transformative process of critical analysis (Shor & Freire, 1987).

Freire (1970b) believes that people should work together to see their world differently, to reform it, and to improve the fate of humankind everywhere. People in the Third World and even in advanced societies, Freire tells us, have been dehumanized by oppressive governments and elites that, through education, propaganda, and the media, have led them to internalize the oppressor's view of them. The aim of education, according to Freire, is to enable people to see themselves and their lifeworld afresh and to transform both so that they can lead more fulfilling lives (1970a). To that end, the powerless must free themselves of stereotypes imposed on them by the dominant class. In Freire's view; education is never neutral; it is either an "instrument of domination," supporting the oppressor's ideas and producing social convention, or else the "practice of freedom" which empowers the oppressed to reflect on their condition and to change it. Following the advice of Freire, we are called to question the situation of marginalized students like Joy as something open and unresolved to be

understood and acted on. This process, which Freire (1971) calls consientization, or consciousness-raising, requires that we focus on the students' actual experiences, abandoning the stereotypes and ideas of the dominant class and strive to reveal these experiences as they really are.

Similarly, McCarthy (1988) speaks through the voice of Freire as he calls for direct cultural interventions in schooling that connect issues concerning the curriculum to radical issues that center on the construction and positioning of oppressed individuals in society. He argues for a research methodology that breaks away from the privileged theoretical and political concerns of the imperial center and listens to the "non-synchronous voices from the periphery" (p. 200).

A highly regarded ethnography by Fine (1991) is raising consciousness about the non-synchronous voices of minority students in our schools. Fine tells a story about race and class privilege and an institutional culture that produces and then justifies the failure of minority students. Her work reflects critically on the institutional policies and practices that enable, obscure, and legitimate dropouts of minority students as if the mass exodus were natural. The institutional culture that made the events in Joy's life possible is mirrored in the lives of these and other students on the edges of society.

There is a line of connection between the alternative transformative curriculum conceptualized by Doll (1988, in press) and the model of teaching espoused by Gadamer (1970). For Gadamer, teaching is dialogue in which two or more persons, all with their own limited point of view, reach an understanding they had not anticipated. Genuine dialogue allows the truth to be revealed and to be seen by each participant; openess on both sides is essential in the give and take of the dialogue as preconceptions are thrown off or modified. Successful dialogue, according to Gadamer, transforms both teacher and student: "The participants part from one another as changed beings. The individual perspectives with which they entered upon the discussion have been transformed, and so they are transformed themselves." (Gadamer, 1981, p.110). This hermeneutical approach to understanding and learning is a prominent theme in the manifestation of a transformative curriculum.

In a model akin to that proposed by Doll, the conception of "a construction zone" is offered by Newman, Griffen, and Cole (1989). Following the work of Vygotsky, these scholars introduce the concept of "a construction zone" where there is a chemistry as a person engages with another that allows one mind to appropriate another's thinking and new meanings are provoked.

The story of Joy is not far removed from the concerns of Oliver Sacks, a prominent physician and clinical writer.

Sacks (1990) reveals stories of persons struggling against incredible adversity that enable the reader to enter the worlds of persons who have neurological impairments and to imagine what it must be to live and feel as they do. Sacks' work problematizes the deficit-driven medical model that separates body and mind and often ignores the persona, the interior of life, the self.

Alternative Views of Special Education

Meyen and Skrtic (1988) offer a progressive critique of the field of Special Education. The authors argue for alternative perspectives that challenge the traditional view of the field and the world within which it operates. Bogdan & Knoll (1988) present such a view in their call for the discipline of sociology as an important frame of reference within which to study special education and the concept of disability. The authors support qualitative research and life histories in particular as an avenue to free preconceived notions and prejudices about persons who have disabilities. Additionally, they challenge professionals "to demystify themselves and join in a creative dialogue in which they can freely share some of their understanding and skills with others who, in turn, can help them to a more holistic awareness of the people they serve" (Bogdan & Knoll, 1988, p.476). The thesis of Bogdan & Knoll's (1988) work is reflected in Janesick's (1988) convincing argument that understanding the relationship among minority status,

poverty, and special education means considering the cultural and social context within which they exist.

Meyen & Skrtic (1988) remind us that criticism of special education knowledge and practice flows over into a criticism of the knowledge base and practice of general education. The authors briefly trace the political and moral campaign of the 1960s and 1970s that led to the passage of EACHA to provide the way for discussing a renewal of the struggle for appropriate education in the least restrictive environment. Acknowledging that EACHA has fallen short of its anticipated effect for most students, Meyen & Skrtic maintain that a new struggle for appropriate education in the least restrictive environment "must be informed by a broader, more comprehensive understanding of the social, political, cultural, organizational, and economic interrelationships within which education, reform, and 'disability' exist" (p. 538). The authors stress that to win the new struggle, the field of special education must be open to criticism and reorient its knowledge base. In order not to repeat the same mistakes as in the past, they warn that special education must reorient its professional knowledge base to correct its narrow assumptions about the nature of disability, education, and progress. They advise that we must also be able to recognize and confidently, persistently, and forcefully communicate contradictions in current school organizations. Meyen & Skrtic emphasize that

we can never again assume that our knowledge base and professional practices are inherently correct. Moreover, they urge that "we must enlarge the debate and be willing to call the entire system of public education into question.... We must be sufficiently courageous and informed to question the morality of various social, political and economic institutions which, in conjunction with education, act to create and maintain the notion of 'the other' in our society" (p.538).

In line with Heshusius' call for a holistic model of special education is a proposal by Guess & Siegel-Causey (1988) for a holistic view of education for children and youth with severe disabilities. They remind us that current educational practices follow a "Let's fix it" (p. 320) model that views the child as little more than a collection of deficits. It is a model that focuses on differences and behaviors that are not consistent with the expectations of those trying to change them. Lost in this approach is an appreciation for how persons with disabilities can impact positively on others.

Guess & Seigel-Causey (1988) express hope that in the future the approach will be different; "that the student will be recognized as a whole person, a totality, not just a responder to stimuli" (p. 319). They stress that all of the internal motivating factors and conditions, emotions, complex cognitive processes, and other psychological

parameters which interact with the environment to produce human behavior must be considered.

In his comprehensive critical analysis of school organization, *Behind Special Education,* Skrtic (1991) imparts his view of the severe and profound disability area. Programs for students with severe and profound disabilities represent the actual case of the ideal *adhocratic* configuration (an adaptable problem-solving organization in which interdisciplinary teams of professionals faced with uncertain work and dynamic conditions collaborate to invent personalized programs). He draws this conclusion based on the following aspects of programs for students with severe disabilities: (a) the needs of the students are so variable that the notion of a standard program is virtually precluded, (b) the complexity of diagnostic and instructional problems is so great that interdisciplinary collaborating is required and, (c) the professionals ordinarily have a close working relationship with the students' parents. Consequently, Skrtic (1991) asserts, "These programs and the professionals that work in them are prototypical of the school organization and professional culture that are needed for education in the 21st century" (p. 213). He further argues that EACHA can work for students with disabilities only if it becomes the basic value and organizing principle for all of public education. As such, it "would mean the end of education as mass-

produced schooling and the beginning of an era of respect for and nurturance of each student as a unique and ultimately valuable individual" (Skrtic, 1988, p. 517).

Review of Discoveries

Virtually everything to be said about the education of children who have severe disabilities pertains equally well to general education. Education for all children, including those with severe multiple disabilities, depends on clear commitment and directed action guided by the following beliefs that promote real learning.

1. Every child is a whole person and a valued individual. Differences are celebrated and accommodated.
2. Education is choice and voice and learning to live a human life under all kinds of circumstances. Educational practice that takes inner goal-directness and inner mean-making to be the primary characteristics of human life and learning nourishes the interior of the child.
3. Interaction precedes learning. More than appropriate methodology and techniques, education triumphs when the notion of learning as a communal process permeates the social experience of schooling.
4. Mutual, reciprocal, or helping relationships among parents, teachers, other school personnel, and the child are shared social experiences that ground

interaction into real life significance and foster a holistic awareness of the child.

5. Evaluation is a communal process that assesses qualitative changes in the child over time.
6. Various social, political, and economic institutions act to create and maintain the purposes of schooling in our society. The destiny of the child is improved when educators and parents, as well as the general public, are sufficiently informed and work together to take up the challenge to act on institutional practices and procedures that [re]produce social inequities.

New Questions

Research is useful because it broadens our knowledge of the people, the setting, or the event studied. Equally significant is that it frames new issues and generates new questions (Sutton, 1988). The life history of Joy discloses a number of concerns.

Through studies such as this, researchers and practitioners in the field of special education are reminded of their tremendous responsibility toward students like Joy whose lives are affected greatly by the practices and procedures they institute and the services they provide. In addition, by taking the insider's view, life histories show that differences in the way children with severe disabilities view themselves is not attributable entirely to diminished intellectual capacity or to the severity of their

physical impairments. When the details of a child's past and present life are analyzed, they reveal the social forces that affect a child's sense of self and account for many of the ways the child encounters the world.

This study presents the life story of only one child and the views of her parents and significant others in her life; more life histories of other individuals who have severe disabilities are needed to fill in the research gap. As this population continues to increase and these children become more visible in our schools and in our communities, more research is needed to address the needs of this population.

In regard to qualitative/interpretive research, Ferguson, Ferguson, & Taylor (1992) specify that the area of severe multiple disabilities is particularly hard for interpretivism to explore extensively. The scarcity of the research is due in part to the difficulty in conceiving the social world of individuals whose experience of concepts and communication is so uncertain for us. "The relativity of language seems a woefully inadequate explanation" (p.297). Ferguson et al. (1992) maintain even if some of these individuals "do not noticeably interpret experience for themselves in any strong sense of human agency by telling their own stories, the social text remains--containing their contribution--for others to interpret. People do not have to talk to tell their stories, and those stories can have

meanings that their authors will never know" (p. 298).

For Ferguson et al. (1992), disability is an experience waiting to be described--a social construction of multiple experiences waiting to be recognized. So, too, is humanness. In an interesting turn in interpretive research in the disability field, Bogdan and Taylor (1992) searched for the perspectives that sustain the beliefs of nondisabled persons in the humanness of their partners who have severe disabilities. Their interest was in understanding how nondisabled persons who do not stigmatize, stereotype, and reject individuals who have severe disabilities define those individuals. More research is needed on the socialization of humanness. Who are the people in schools most accepting of children who have severe disabilities? How can more people learn to connect, to know, and to value these children? If connecting is the key, how can we provide more opportunities for everyone to connect?

As we include more children who have severe disabilities in our schools, ethnographic studies of classrooms are needed to understand the culture of the classroom. What does inclusion look like? How does it work? How are alternative learning principles translated into practice in a classroom of students with extreme ranges of abilities? What is the quality of teaching and learning?

More research is also needed on alternative perspectives and different implications for curriculum,

teaching, and learning. How does an alternative approach manifest itself in the lives of other marginalized students?

In the area of severe multiple disabilities, research teams comprised of teachers, school administrators, physicians, therapists, the family, social workers, and others are needed to improve the destiny of the whole child.

Afterthought

It was my intent to deliberately use language in this study with as little special education and medical jargon as possible. I am guided by Schon's (1983) observation that jargon hinders creative thinking by separating the "knowers" from the outsiders. Likewise, I purposefully used as few disability labels as possible. I do not wish to contribute in any way to categorizing children into narrow stigmatized groupings that create images of personal deficit rather than images of potential. However, at some point in the study, I caught myself falling into the trap of mechanistic thought and concepts, referring to the labels and categories assigned to children in special education. I therefore revised the narrative as much as possible to avoid fixing Joy and the other children mentioned in this study into narrow groups.

As life's turnings would have it, with the closure of JTS Special School, my professional journey led me away from education for children with severe disabilities. Conducting this study, however, has put me back on the path. The

detour has also changed me. I see the world holistically now, more than ever before. Thank you, Joy.

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APPENDIX A

MAIN CODING CATEGORIES

ACTIVE

AUTONOMY

BARRIER

COLLABORATION

CONTINUITY

CONTROL

DISCONTINUITY

FRAGMENTATION

INCLUSION

MAINTENANCE

MODIFICATION

NEGATIVE ACTION

NEGATIVE ATTITUDE

PARENT-PROFESSIONAL RELATIONSHIP

PASSIVE

POSITIVE ACTION

POSITIVE ATTITUDE

POSSIBILITIES

SEPARATION

STUDENT-TEACHER RELATIONSHIP

APPENDIX B

IEP GOALS AND OBJECTIVES FOR JOY
FROM BOTH OF HER SCHOOL PROGRAMS

CURRICULUM AREA: SELF-HELP	
JOHNSTON SPECIAL SCHOOL 10/7/85	EVANSVILLE SPECIAL SCHOOL 9/21/88
ANNUAL GOAL: Improve oral motor skills and hand-to-mouth patterns. 1. When textured or soft foods are placed between the molars, Joy will move her tongue to that side (right and left sides should be alternated). 2. When textured or soft food is placed between molars, Joy will attempt to chew food. 3. Given a bowl of preferred foods (whipped cream, pudding, applesauce, cereal) [placed] in front, Joy will spontaneously dip her finger into the food and bring it to her mouth.	ANNUAL GOAL: Joy will accept food and liquid from several different caretakers and achieve this 100%. 1. Given lunch period, Joy will allow a spoon to be placed near her mouth and accept food. 2. Given the lunch period, Joy will accept liquid from a cup and drink one cup [of liquid] every day.

CURRICULUM AREA: MOTOR	
JOHNSTON SPECIAL SCHOOL 10/7/85	EVANSVILLE SPECIAL SCHOOL 9/21/88
ANNUAL GOAL: (OT) Develop improved functional usage of the right & left upper extremities and improve reaching & grasping skills.	ANNUAL GOAL: (PT) Maintain or improve passive range of motion throughout trunk & extremities/improve gross motor level.

Appendix B

CURRICULUM AREA: MOTOR [continued]

JOHNSTON SPECIAL SCHOOL	EVANSVILLE SPECIAL SCHOOL
1. After Joy is placed on her stomach & bearing weight on both elbows with head held at 45 degrees or more 7 and hands positioned to hold musical toy, Joy will maintain this position.	1. Using standing table in classroom, child will be stood daily for physiological benefits.
2. Sitting in corner chair & following relaxation to right arm & hand, Joy will maintain grasp of a toy.	2. Improve/maintain passive range of motion
3. While on stomach on large ball, following rocking for relaxation, Joy's arms will be placed outstretched (shoulders extended) & maintain in a relaxed state.	3. Improve gross motor level (sitting balance, equilibrium & protective reactions)
4. In corner chair, given a musical toy positioned at shoulder level, Joy will reach up with her left hand to activate the toy.	
5. While sidelying, hips flexed & head flexed on pillow, Joy will reach toward a toy with her left hand (left hand being on top).	
6. While sidelying on left side, hips & head flexed, Joy will reach with her right hand.	

Appendix B

CURRICULUM AREA: SOCIAL/EMOTIONAL

JOHNSTON SPECIAL SCHOOL 10/7/85	EVANSVILLE SPECIAL SCHOOL 9/21/88
ANNUAL GOAL: Joy will show increased awareness of others and develop interaction with others.	ANNUAL GOAL: Joy will respond to finger plays and games [initiated] by trainer--imitate vocally or gesturally [without assistance]--develop interaction with staff and peers.
1. Interplay with others	1. Given classroom setting, Joy will cooperate with trainer and achieve success in imitating either vocally or gesturally simple games imitated by trainer.
2. Interact with toys with others	2. Given classroom setting, Joy will actively seek attention from peers or staff.
3. Repeat vocalizations	3. Given a play setting, Joy will play approximately... 5 to 10 minutes.
4. Offer toy to others	
5. Play "peek-a-boo"	
6. Indicates need for adult help with mechanical toy	
7. Express emotions by voice or action in at least 2 different ways	
8. Regularly inhibit activity to "no"	
NOTE: Action words in Joy's objectives were underlined for emphasis by Joy's teacher.	

Appendix B

CURRICULUM AREA: COGNITION

JOHNSTON SPECIAL SCHOOL 10/7/85	EVANSVILLE SPECIAL SCHOOL 9/21/88
ANNUAL GOAL: Joy will show development in cognitive areas by displaying imitation and play skills, developing problem solving skills and object permanence skills. 1. Imitate actions (adapted to actions not involving vision) 2. Play with a variety of objects in an appropriate way 3. Find partially hidden objects (adapted to finding by ways not involving vision) 4. Combine toys in motor play 5. Indicates to adult desire to restart mechanical toy 6. Remove[s] object from open container [by] reaching into container 7. Drops and picks up toy (instead of "pick up," grasp, shake, squeak or rattle) 8. Retrieves object on flat surface by pulling attached string 9. Touches adult's hand or toy after adult has activated toy	NOTE: Specific goals and objectives to address cognitive domain were not included in Joy's IEPs from Evansville Special School.

Appendix B

CURRICULUM AREA: COGNITION (continued)	
JOHNSTON SPECIAL SCHOOL	EVANSVILLE SPECIAL SCHOOL
10. Imitate[s] an action or sound that was experienced earlier 11. Place[s] object into container after having removed it	No goals and objectives (see note on previous page)

CURRICULUM AREA: SENSORY INTEGRATION	
JOHNSTON SPECIAL SCHOOL 10/7/85	EVANSVILLE SPECIAL SCHOOL 9/21/88
NOTE: Specific goals and objectives to address sensory integration were not included in Joy's IEPs from Johnston Special School.	ANNUAL GOAL: Joy will tolerate trainer involving her in sensory activity without resistance 100% 1. Given the classroom setting, Joy will tolerate trainer stroking her face and especially near her mouth--and will not be resistant to other tactile activities

APPENDIX C

GENERAL DESCRIPTIONS OF JOY IN IEPS FROM BOTH OF HER SCHOOL PROGRAMS

JOHNSTON SPECIAL SCHOOL
IEP dated 9/21/87

GENERAL STUDENT INFORMATION
Joy has developed in the [pre]academic area this past year by developing cognitive awareness and environmental control. She has learned to combine toys in motor play to achieve interesting results. She has learned to repeat a movement with a toy...or switch to achieve a desired result, such as music or making a toy work. She will continue to work on [acquiring] cognitive skills through hearing, touching, sensory awareness and self-expression.

EVANSVILLE SPECIAL SCHOOL
IEP dated 9/21/88

GENERAL STUDENT INFORMATION
Joy has severe delays in all developmental areas--she has cerebral palsy--vision impaired--requires support for sitting--non-ambulatory--a few isolated works--no self-help skills. Joy is friendly--responsive to music.

APPENDIX D-1

DATA RECORD FORM

JOHNSTON SPECIAL SCHOOL

Data Record Form

Student: Joy Hamilton	Date Begin 9/9/87	Date End
Teacher/Therapist	Paraprofessional: Judy	

Objective No.: M4

Objective: Sitting in the corner chair & given a noisemaking/musical toy which is periodically moved slightly from center leftwards or upwards Joy will adjust her left hand to search for and find the toy 4 x a session.

Levels of Independence	Task Analysis	3 of 5 days
1. independent	1. 1-2x	
2. non-physical prompt	2. 3x	
(verbal, gestural	3. 4x	
within-stimulus, model)	5.	
3. minimal physical prompt	6.	
4. full physical prompt	7.	

Date	Comments/Re-enforcers	L*	S*	Trials						
11/9	did very well	2	3	0	+1	2	3	4	5	6
11/10	She really enjoys this game.	2	3	0	+1	2	3	4	5	6
11/11	Joy Lynn needs more games of this	2	3	0	+1	2	3	4	5	6
	kind. She loves it.	2	3	0	1	2	3	4	5	6
11/12	Joy has been doing well.	2	3	0	+1	2	3	4	5	6
11/13	didn't seem very interested	2	3	0	+1	2	3	4	5	6
11/16	was able to accomplish, but wasn't	2	3	0	+1	2	3	4	5	6
	in good mood	2	3	0	1	2	3	4	5	6
11/17	Used monkey bells for first time,	2	3	0	+1	2	3	4	5	6
	also put them on her head	2	3	0	1	2	3	4	5	6
11/18	enjoys this game	2	3	0	+1	2	3	4	5	6
11/19	put it on her head	2	3	0	+1	2	3	4	5	6
11/20	can find a toy faster as we practiced	2	3	0	+1	2	3	4	5	6
11/30	absent - home	2	3	0	1	2	3	4	5	6
12/1	absent - home	2	3	0	1	2	3	4	5	6
12/2	did very well - hasn't forgotten a thing	2	3	0	+1	2	3	4	5	6
12/7	is able to find toy easily	2	3	0	+1	2	3	4	5	6
12/8	does well	2	3	0	+1	2	3	4	5	6
12/9	w/Sammy	2	3	0	+1	2	3	4	5	6
12/10	this is beginning to be old hat!	2	3	0	+1	2	3	4	5	6
	can do but has lost excitement	2	3	0	1	2	3	4	5	6
12/11	did well	2	3	0	+1	2	3	4	5	6
12/15	alert	2	3	0	+1	2	3	4	5	6
12/16	did well with "Mikie" and suction	2	3	0	+1	2	3	4	5	6
	toy held in different positions	2	3	0	1	2	3	4	5	6
12/17	field trip	2	3	0	1	2	3	4	5	6
12/18	no problems	2	3	0	+1	2	3	4	5	6
12/21	enjoyed very much	2	3	0	+1	2	3	4	5	6
1/4	We are back in school from vacation	2	3	0	+1	2	3	4	5	6
	and Joy hasn't forgotten a trick.	2	3	0	1	2	3	4	5	6
1/5	anxious to play "Mikie"	2	3	0	+1	2	3	4	5	6
1/6	did well	2	3	0	+1	2	3	4	5	6
1/11	out for hip surgery	2	3	0	1	2	3	4	5	6
1/14	did not do surgery/expect her tommorrow	2	3	0	1	2	3	4	5	6

* L=Level S=Step

APPENDIX D-2

DATA RECORD FORM

Evansville

Name Joy Area Motor # ____ Objective: Position

--- active refusal Unit _____ Standing Table

G = gross physical # _____ (25 min.)

P = partial physical or gestural Command: _____

V = verbal

A = independent _____

DATE	TRAINER	SR+	STEP	MON	TUES	WED	THURS	FRI	DATE	TRAINER	SR+	STEP	MON	TUES	WED	THURS	FRI
2/27-3/3				sick	45	45	sick	sick	5/15	Dean					ABSENT		
3/6				AB	45	45	45	---	5/16	Dean					ABSENT		
3/13				45	45	45	45	45	5/17	Dean					ABSENT		
3/20				45	AB	AB	AB	---	5/18	Dean					No Standing		
4/3				45	45	45	45	45	5/19	Dean					No Standing		
4/10				45	45	45	---	45	5/22	Dean					No Standing		
4/17				45	--	45	45	--	5/23	Dean					No Standing		
4/24				--	--	45	45	--	5/24	Dean					No Standing		
5/1					--	45	45	45	5/25	Dean					Slept All A.M.		
5/8				.													
5/11				ABSENT													
5/12				ABSENT													

COMMENTS:

(Note: AB=absent; 45=45 minutes)

APPENDIX E

EXCERPT FROM LETTER REGARDING SUGGESTIONS FOR JOY'S PROGRAM

To: Margaret Smith
From: Phyllis Leone
Date: March 16, 1990

Mrs. Lopez has asked for my suggestions, and per my telephone conversation with you yesterday in which you agreed to discuss some specific suggestions that I may have..., I offer the following possibilities for you and your staff to explore that may enhance Joy's program and perhaps improve her level of functioning:

1. MOBILITY
   The biggest challenge may be to give Joy a means to move about and explore. The possibility of a walker as suggested by the parents and contingent upon [the] approval of her orthopedist should continue to be explored by the PT.

2. HEAD CONTROL
   Close consultation with the PT and OT to decrease abnormal posture as a result of the tendency for Joy to drop her head forward most of the time is suggested. An adapted micro switch placed at or near the back of her head to activate a cassette recorder may be reinforcing and perhaps increase her motivation to hold her head erect. The use of a walker and positioning prone over a wedge, bolster, or vestibular ball may also improve Joy's head control.

3. VERBAL COMMUNICATION
   Joy once used a few one and two-syllable meaningful "words" consistently and appropriately, i.e., "Mama", "Dada", "mu" for music, "ice", and "bee bee" for baby. Consultation with the SLS [speech and language specialist] to develop a concentrated approach for teaching Joy to verbalize for familiar objects, people, and places may be helpful.

4. SENSORY STIMULATION
   Any residual vision that Joy may have could be stimulated with reflecting toys and objects. Brightly colored bracelets on her lower arms and wrists may...stimulate body awareness as well as functional vision.

   Tactile stimulation of her school environment during the normal course of the day can be enhanced with the aid of a mobility device.

5. FINE MOTOR SKILLS
Consultation with an OT to suggest the most appropriate positioning of the plate switch should maximize Joy's useof the switch.

6. COGNITIVE FUNCTIONING
Experiment with ways to allow Joy to make choices, i.e., foods, toys, favorite places. Give her the opportunity to explore other areas of her school. As she passes through various stages of development increase the distance and complexity of the route she must travel to reach her favorite place. Because she already demonstrates the motivation to move, she may begin to recognize objects and relate them to specific locations. Encourage her to explore and form a cognitive map of her classroom, her school, and her playground. Encourage her to problem solve.

7. CO-ACTIVE AND INDEPENDENT FEEDING
Teach Joy to locate her plate and glass and touch her food to identify it. Co-actively manipulate Joy when feeding her with a spoon. Begin with a few spoonsful and increase the number of repetitions.

Encourage finger feeding. The OT may suggest soft foods for this purpose, i.e., small pieces of banana, kiwi fruit, very small bits of cold meat, soft cheese, etc.

8. ORAL-MOTOR INTEGRATION
A teaspoon of rice added to pureed vegetables will provide a different texture for Joy and may accustom her tongue to manipulate small lumps. Chewing may be developed with the use of bits of food and techniques as recommended by the OT to prevent aspiration. Gum massage and coordinated movements of her lips, mouth, and tongue may also improve her ability to produce words and sounds.

9. TOILETING
Perhaps the idea of toilet training Joy should be explored. Her mother states that Joy "wets" only 2 or 3 times a day when she is home and that Joy's bowel movements are controlled with medication. A schedule to allow her to sit on an adapted toilet 2 or 3 times a day may lead to some success at toileting.

10. POSITIONING
Use of pillows and soft toys may be used to signal rest time and other floor activities. Consultation with

OT/PT to ensure proper sidelying position at rest time should be helpful. Her position should be changed regularly so that she is exposed to a variety of visual fields. Massage during rest time may decrease tightness in Joy's limbs. Applying skin cream can promote body awareness.

11. WEIGHT BEARING

OT consultation to position Joy for sidelying and weight bearing on one elbow while reaching and grasping with the other hand should be explored.

12. BALANCE AND SITTING
Activities to encourage independent sitting and reaching with a purpose should be explored.

13. INTERACTION WITH PEERS
The possibility of allowing Joy to participate in music class with children who are able to sing and verbalize should enhance her vocalizations.

Considering that she responds so well to music, perhaps this arrangement can be made not only at Evansville but [also at Eastside Elementary when children from Evansville are bused to the school weekly for interaction with nondisabled peers].

A suggestion that may be helpful to the parents is a support group. Joy is approaching puberty and her mother has concerns about feminine hygiene needs for Joy...Perhaps there are other parents and/or literature that you can suggest that may be helpful to Joy's mother and father.

[Note: Some of these suggestions were adapted from McInnes, J. M. and Treffry, J. A. (1982). *Deaf-Blind Infants and Children: A Developmental Guide*, Toronto: University of Toronto Press.]

APPENDIX F

THERAPY RECOMMENDATIONS FOR JOY FROM SHRINERS' HOSPITAL

SHRINERS HOSPITALS FOR CRIPPLED CHILDREN

March 23, 1990

Re: Joy Lynn Hamilton

Therapy Recommendations

Occupational Therapy
Frequency - 2x per week, 45 minutes

Objective #1

Decrease elbow flexion posturing:

a) utilize extension splints for 30 minute intervals during periods of decrease activity such as naps, night resting, (30 minute intervals implies 30 minutes on, 30 minutes off, etc. for a cycle of 1 hour total wearing time);
b) utilize elbow extension splints during therapeutic handling and developmental activity practice sessions to focus on proximal stability and facilitate distal grasp/release training (i.e., computer training?, etc.).

Objective #2

Decrease humeral adduction and internal rotation:

a) place child prone over a wedge with elbows extended (splints would be appropriate here) and axillae resting over the end of wedge to facilitate remediation of flexor tone;
b) place laptray on wheelchair during therapeutic and feeding activities.

Objective #3

Increased listening skills:

a) use musical toys and encourage appropriate responses, i.e. turning to music, grasping for toy, verbalization, etc.

Therapy Recommendations
Joy L. Hamilton
Page 2

Objective #4

Prevent increased hand-wrist-finger flexor deformities:

a) utilize static hand splints bilaterally for complete period of night resting if possible (if possible means if the child does not develop increased redness that would compromise skin integrity 2° splint wear, not if the child does not cry or resist splint wear.)
b) weight-bearing upper extremity work in prone over wedge or side-sitting (elbow extension splints useful here too).

Physical Therapy
Frequency - 2x per week, 45 minutes

Sidelying activities

a) to promote hands and arms to midline with legs in neutral.

Prone activities

a) to promote UE (forearm and hand) weight-bearing;
b) head and neck extension;
c) and upper trunk extension.

Sitting in corner chair with abduction pad

a) to allow UE weight bearing on tray and encourage head and neck extension;
b) and allow free play with toys on tray.

Standing for 45 minutes 2x per day

a) to promote LE weight bearing with full knee extensions and neutral feet;
b) standing in spider walker 2x per day for 20 minutes at a time.

Ball activities

a) to promote trunk righting and protective extension reactions

Appendix F

Lower extremity PROM and stretching

If you have any questions, please feel free to contact the Rehab. personnel listed below. Thank you for your participation in this child's case (our # is 604-222-5704, xx. 128 and 129).

Joseph Bologna, O.T.R./L
Occupational Therapist

Mary Ann Jones, R.P.T.
Physical Therapist

Bryson T. Burns, M.D.
Chief of Staff

cc: Parents
Johnston Training Center
Evansville Special School
O.T. and P.T. records

APPENDIX G

ROBERT HAMILTON' S HANDWRITTEN
NOTES FOR APRIL 14, 1990 IEP CONFERENCE

Would like to see:
All of the recommendations from Shriners Hosp[ital] be implemented into Joy' s program, as well as other suggestions made to staff.

1. Weight bearing for her upper extremities to reduce rounded shoulders
2. Vestibular ball, wedges, bolsters
3. Walker used
4. PT
5. OT
6. Speech Therapy
7. APE
8. Stimulate oral motor skills to keep Joy from using her tongue to explore. Use hands instead.
9. Cognitive: Want Joy to have more challenges, to be able to make more choices as far as toys, switches, food, music, etc. Give her opportunity to explore more of her surroundings.
10. Encourage problem solving
11. Balance & sitting up
12. Toileting
13. More interaction with children her age who are normal (able to verbalize and do more)

* It' s sad when parents have to use outside sources in order to get the program back to what the child was getting previously.
* It' s bad when we have to recognize that there' s a problem before anything gets done about it. Example: Tightness in arms, loss of head control and oral motor.

Attitude

* Need to be able to walk around in the classrooms with the students' eyes to see if they would learn anything in this atmosphere. Think like they do.
* Not a negative narrow minded attitude.
  We feel Joy has to prove herself before she can move on or have any more added to her program. [They] don' t believe she can do things we tell or suggest. They' ve given us the impression that they just don' t know what to do with Joy or how to stimulate her. (She' s a mystery, I just couldn' t get her to do anything, She just wore me out, She[' s] done more for ya' ll (parents) than she' s done for me [teacher] all year.)
  Could have easily figured Joy out if they would have called us or [Joy' s] past teachers.

Appendix G

* It' s my hope that we can all learn from this conference... In all reality, Joy has lost 1-1/2 years because of the lack of a continuance in her program.
* In the past she was used to getting PT, OT, APE, and speech therapy. In this program we have only seen her [get] speech therapy and APE. It' s as if her program has been cut in half.
* We don' t want just passive efforts for Joy. Not requiring [her] to exert any effort to do anything. Not just Joy can tolerate this & that.
* Why sign? (IEP) We put our faith & trust in your program, and we felt that as time progressed there would be more objectives added to the program. We' ve been very frustrated that our suggestions & input was not followed up on. We felt that by ya' ll having access to Joy' s past IEP' s & other records, that her program would soon be updated.
* Suggestions about contacting past teachers was never followed up on.
  We were used to the teachers and therapists in the past coming to us with areas of concern about Joy, and we would see that she was taken to Shriners or [the staff] was given new ideas that would help.
* You are the experts and you should have noticed a regression.

VITA

Phyllis James Leone grew up in Winnfield, Louisiana. She majored in elementary education at Louisiana Tech University where she earned a bachelor's degree in 1972. She earned a master's degree in education with a major in special education from Louisiana State University in 1977. Phyllis has served as a regular education teacher, a resource room teacher, an Individual Education Program Coordinator, a special school principal, and an assessment teacher. Her research includes an independent scudy in February 1990 of the education and habilitation programs of one of Louisiana's state-operated institutions for the Office of Mental Retardation/Developmental Disabilities. A letter to the editor was published in the *Journal of Learning Disabilities* in 1990. Currently Phyllis is co-authoring an article on the Total Program Photo Essay for publication. Areas of special interest include holistic education, education of infants and preschoolers with severe disabilities, interpretive research in education, and special education technology.

DOCTORAL EXAMINATION AND DISSERTATION REPORT

Candidate: Phyllis James Leone

Major Field: Education

Title of Dissertation: The Difference that Made a Difference: Nuances of a Transformative Curriculum in the Life History of Joy Hamilton, a Child Who Has Severe Disabilities

Approved:
Co-Chairs

Major Professor and Chairman

Dean of the Graduate School

EXAMINING COMMITTEE:

Date of Examination:

May 15, 1992